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# Stratifying Health Care Quality Measures Using Socio-demographic Factors

Minnesota Department of Health

*Report to the Minnesota Legislature 2015*

**March 2015**

# Stratifying Health Care Quality Measures Using Socio-demographic Factors

**March 2015**

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*Protecting, maintaining and improving the health of all Minnesotans*

March 12, 2015

The Honorable Kathy Sheran  
Chair, Health, Human Services and Housing  
Committee  
Minnesota Senate  
Room G-12, State Capitol  
75 Rev. Dr. Martin Luther King Jr. Blvd.  
Saint Paul, MN 55155-1606

The Honorable Tony Lourey  
Chair, Health and Human Services Finance  
Committee  
Minnesota Senate  
Room G-12, State Capitol  
75 Rev. Dr. Martin Luther King Jr. Blvd.  
Saint Paul, MN 55155

The Honorable Tara Mack  
Chair, Health, Human Services Reform  
Committee  
Minnesota House of Representatives  
Room 545, State Office Building  
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Saint Paul, MN 55155-1606

The Honorable Matt Dean  
Chair, Health, Human Services Finance  
Committee  
Minnesota House of Representatives  
Room 401, State Office Building  
100 Rev. Dr. Martin Luther King Jr. Blvd.  
Saint Paul, MN 55155

Dear Senator Sheran, Senator Lourey, Representative Mack, and Representative Dean:

As required by 2014 Minnesota Laws, Chapter 312 Article 23, Section 10, this report presents findings from a study by the Minnesota Department of Health about stratifying Quality Reporting System measures based on disability, race, ethnicity, language, and other socio-demographic factors that are correlated with health disparities and impact performance on quality measures.

In conducting the study, MDH performed:

- An analysis of its aggregated Quality Reporting System data;
- A literature review of reports and peer reviewed literature related to the capture, collection, and stratification of socio-demographic information for purposes of assessing quality performance and health disparities; and
- Consultation with stakeholders, including: consumers, community and advocacy organizations representing diverse communities; health plans; providers; quality measurement organizations; and safety net providers that primarily serve communities and patient populations with health disparities.

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Eliminating health disparities and creating a culture of health equity in which all individuals have the opportunity to be healthy is among MDH's highest priorities. This report lays out a series of recommendations that offer multiple pathways to stratification that acknowledge both the differing sources of data that make up the Quality Reporting System and the current state of the evidence. Together, these recommendations will help us continue to move forward, together with our provider partners, in creating that future.

If you have questions or concerns regarding this study, please contact Stefan Gildemeister, the State Health Economist, at 651-201-3554 or [Stefan.Gildemeister@state.mn.us](mailto:Stefan.Gildemeister@state.mn.us).

Sincerely,

A handwritten signature in black ink, appearing to read "Edward P. Ehlinger". The signature is fluid and cursive, with a long horizontal stroke at the end.

Edward P. Ehlinger, M.D., M.S.P.H,  
Commissioner of Health

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# Executive Summary

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In 2009, the Commissioner of Health established a standardized set of quality measures for health care providers across the state that built on existing voluntary efforts, with the purpose of creating a more uniform approach to quality measurement. Quality measures define consumers' experiences and perceptions of health care, organizational structure and systems that can lead to enhanced market transparency and drive health care quality improvement. This report provides a summary of the Minnesota Department of Health's (MDH) findings and recommendations for operationalizing the Legislature's 2014 directive for MDH to develop a plan for collecting, analyzing and reporting measures based on disability, race, ethnicity, language, and other socio-demographic factors through the Quality Reporting System.

To develop a quality measure stratification plan, MDH investigated the socio-demographic factors that Minnesota clinics and hospitals collect for quality measurement and reporting initiatives; identified other factors and data sources that could be used in stratification; examined the benefits and weaknesses of the available options; and identified options that Minnesota should consider in stratifying quality measures using socio-demographic factors. MDH also worked with a vendor to conduct extensive interviews with community members to learn about the factors that might facilitate or hinder collection of these data points from patients, and how they should be collected.

## Key findings

- Interviews with community members underscored the importance of building trusting relationships between patients and the health care system; the need for increasing public understanding of the need for collection and use of socio-demographic information; and protection and privacy of data. Community members also noted the importance of providing health equity data to communities so they can be used for health improvement and advocacy.
- In the course of delivering care to patients, most Minnesota clinics collect and store basic socio-demographic information, including patient age, gender, residential zip code, health insurance primary payer, race, ethnicity, language, and country of origin in their electronic health record (EHR) systems. MDH requires clinics to report patient age, gender, zip code, and primary payer through the Quality Reporting System; race, ethnicity, language and country of origin are voluntarily reported by clinics to Minnesota Community Measurement.
- Community variables—such as income, poverty rate, availability of public transportation, types and availability of food outlets, etc.—that are aggregated at the zip code, census tract, or neighborhood level—can also be used, together with variables like zip code, to stratify quality measures to document differences in experiences for consumer groups.
- Like clinics, Minnesota hospitals capture patient race, ethnicity, and language information to a significant extent to meet various federal requirements for quality measurement and health information technology. However, the hospital quality measures that are included in the Quality Reporting System, which are developed and maintained by national organizations, do not include these factors. As such, these data points are not included in the Quality Reporting System maintained by MDH and therefore not available to conduct analysis that could document differences between consumer experiences.
- Patient experience surveys ask respondents for their age, gender, education level, race, and ethnicity; clinics and hospitals can choose whether to receive patient socio-demographic information from their

survey vendors. MDH requires clinics to conduct the patient experience of care survey every other year, but does not require clinics to report patient socio-demographic information as part of their submission.

- Alongside the clinical information that is collected through electronic health records, providers and payers also record administrative data for billing and reimbursement purposes. However, socio-demographic factors are not easily collected on claims, they are not used in claims-based quality measurement, and their inclusion produces concerns regarding the accuracy and cost of patient socio-demographic data transmitted through administrative transactions.
- Other patient socio-demographic factors—such as disability, sexual orientation and gender identity—could be used to stratify health care quality measures. However, lack of a uniform disability definition, patient privacy and discrimination concerns, and perceived limited clinical usefulness of some of these factors impede standardized and statewide data collection and use at this time.

## Recommendations

The full list of recommendations, and associated costs, can be found on page 25 of this report.

RECOMMENDATION 1: MDH should work with vendors and stakeholders to develop a statewide education campaign for providers and patients related to the collection and use of key socio-demographic factors.

RECOMMENDATION 2: MDH should prepare de-identified summary data files and data analyses of quality performance measures stratified by key socio-demographic variables for use by community researchers.

RECOMMENDATION 3: To the extent that case-level data are not obtainable for this work, MDH should analyze and report community variables, or publicly available data at geographic levels of aggregation. In publishing the report, MDH should identify the strengths and limitations of community variables to understand disparities in quality outcomes.

RECOMMENDATION 4: MDH should conduct and publish an analysis of variations in quality of care using currently-collected age, gender, zip code, and primary payer data linked with community variables by August 2017.

RECOMMENDATION 5: MDH should convene stakeholders from diverse communities and population measurement experts to identify and refine the selection of community variables for stratification analysis and report of quality measures. MDH should develop a summary report beginning in August 2017.

RECOMMENDATION 6 - **Option 1:** Minnesota statute and Rule could be modified to require clinics to submit race, ethnicity, language and country of origin data to MDH as part of the Quality Reporting System beginning in 2016. MDH could stratify and produce analyses of quality measures based on these factors, and use data to develop risk adjustment approaches that include these variables pursuant to legislative timelines.

RECOMMENDATION 6 - **Option 2:** Minnesota clinics could continue to voluntarily submit race, ethnicity, language and country of origin data to MNMCM as they have been doing since 2010. MNMCM could use submitted data to publish stratified reports, and to develop approaches to risk adjustment that include these variables.

RECOMMENDATION 7: MDH should work with Stratis Health, the Minnesota Hospital Association (MHA), and the Hospital Quality Reporting and Steering Committee to explore obtaining race and ethnicity information from CMS for hospital measures that are part of the Quality Reporting System, with the goal of reporting back on the results of that collaboration by January 15, 2017.

RECOMMENDATION 8: MDH should monitor the National Quality Forum's trial period in which it will assess the impact and implications of risk adjusting relevant quality measures for socio-demographic factors.

RECOMMENDATION 9: MDH should work in collaboration with the Minnesota Administrative Uniformity Committee, MHA, Stratis Health, the Hospital Quality Reporting and Steering Committee, and other stakeholder and measurement organizations to complete a study that assesses the implications and opportunities for stratifying claims-based measures in the Quality Reporting System and also the alternatives to populating administrative transaction records. MDH should report back on the results of that collaboration by January 15, 2017.

RECOMMENDATION 10: MDH should submit a report to the Legislature in 2017 with recommendations on quality measurement and disability that are aligned with the Olmstead Plan and federal standards.

RECOMMENDATION 11: MDH should obtain de-identified Minnesota patient experience survey data from the Consumer Assessment of Healthcare Providers and Systems (CAHPS) Database Management Committee to assess the volume of socio-demographic data collected through this survey and identify methods for stratifying patient experience metrics by the available and appropriate socio-demographic variables, and report back to the Legislature in 2017.

# Introduction

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Although Minnesota ranks among the healthiest states in the nation, it simultaneously experiences significant and persistent disparities in health outcomes for some segments of the population. To eradicate these disparities, it is important for the State to foster health equity, which means creating the “conditions in which all people have the opportunity to attain their highest possible level of health,” (MDH, *Advancing Health Equity in Minnesota*, 2014). One of the challenges related to developing and evaluating programs to address and eliminate health disparities is the relative lack of data on many of the contributing socio-demographic factors (MDH and DHS, 2011), including data directly available to communities that are most impacted by health disparities and inequities.

Minnesota has led the nation in its efforts to measure and report on various aspects of clinical quality. After a number of years of voluntary reporting, Minnesota has been requiring the collection of quality measurement data from physician clinics and hospitals since 2009 through the Statewide Quality Reporting and Measurement System (Quality Reporting System). Generally, this data is reported at the facility level, demonstrating overall performance of a provider entity on the rate at which patients receive optimal care in various categories of health care services.

At this summary level, communities, policy makers and stakeholders typically cannot distinguish the quality of care received by lower income patients, patients who live in certain geographic areas, patients in different age groups, or patients with other socio-demographic characteristics, such as race, ethnicity, language, income, or housing insecurity. This limitation means that variation in the quality of care may mask underlying circumstances and factors that have been shown to influence both the acuity of a patient’s health condition and their ability to respond medically to high quality treatment.

Socio-demographic characteristics are important for understanding system-wide variations and disparities in quality of care because evidence shows that many of the factors that most heavily impact a person’s health status exist outside of the healthcare system. These include factors such as income, education level, neighborhood assets, access to healthy food, and housing stability. While a healthcare provider may not be able to directly influence many of these factors, a deeper understanding of them can impact the type of care that the provider recommends, the likelihood that the care provide will actually improve the patient’s health status, or the types of supportive services that may be necessary for the patient as part of any treatment regimen. The recognition of such factors in the delivery and measurement of care has strong support in multiple sectors, including the state’s largest businesses and employers, who specifically recommended expanding quality measurement to address recognized gaps and omissions as a strategy to better assess disparities.<sup>1</sup>

Reporting on quality of care in the absence of socio-demographic characteristics is overly simplistic at best. At worst, reporting quality of care data that lacks socio-demographic considerations may actually deepen the inequities and disparities that currently exist in our health care system by creating incentives for providers to minimize or avoid treating patients from communities that experience disparities and are less likely to contribute to strong performance on existing measures of quality of care (NQF, 2014b). One way to combine socio-demographic factors with quality measures is to report measure results by different

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<sup>1</sup>Minnesota Business Partnership, *Minnesota’s Health Care Performance Scorecard* 30, Jan. 2015, [mnbp.com/wp-content/uploads/2015/02/MBP\\_HealthScorecard.pdf](http://mnbp.com/wp-content/uploads/2015/02/MBP_HealthScorecard.pdf).

groups or combinations of groups—also known as “stratifying” results.<sup>2</sup> Stratification enables the identification of healthcare disparities for certain patient groups and it can unmask healthcare disparities by examining performance for groups who have been historically disadvantaged compared to groups who have not been disadvantaged.

Recognizing these issues, in 2014 the Minnesota Legislature directed MDH to develop an implementation plan for stratifying Quality Reporting System measures based on disability, race, ethnicity, language, and other socio-demographic factors that are correlated with health disparities and impact performance on quality measures (Appendix A).<sup>3</sup> The legislation requires MDH to develop the plan in consultation with: consumer, community and advocacy organizations representing diverse communities; health plan companies; providers; quality measurement organizations; and safety net providers that primarily serve communities and patient populations with health disparities.<sup>4</sup> This report provides a summary of MDH’s findings, conclusions, and recommendations for operationalizing the Legislature’s directive.

## Background

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### Quality Measurement in Minnesota

Minnesota clinics, hospitals, and health plans have a rich history of health care quality measurement through private-public initiatives such as the Minnesota Health Data Institute; collaboratives, such as the Institute for Clinical Systems Improvement; adoption of the National Committee on Quality Assurance’s Health Care Effectiveness Data and Information Set (HEDIS); purchasing initiatives such as the Buyers Health Care Action Group (now the Minnesota Health Action Group); and voluntary data submission of Minnesota-grown outpatient measures through MN Community Measurement (MNCM). The Minnesota Hospital Association (MHA) and Stratis Health have long supported hospital quality measurement and improvement activities for federal and state initiatives. MHA collects data from hospitals, including administrative claims data, and uses it in benchmarking and other analysis.<sup>5</sup> Stratis Health leads a Quality Innovation Network as part of the Centers for Medicare & Medicaid Services (CMS) Quality Improvement Organization Program. It has served Minnesota through this program since it began during the 1970s.<sup>6</sup> Stratis Health helps providers and consumers with the collection and use of data for quality assurance and improvement, and it assists provider organizations to submit data for public reporting.

Prior to the passage of state health reform in 2008, payers were using a variety of health care quality measures to assess provider performance, resulting in substantial reporting burden and inconsistencies in reporting. To better coordinate measurement activities, establish a common set of metrics, and publicly

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<sup>2</sup>“Stratification” refers to calculating health care performance scores separately for different patient groups based on some characteristic (NQF, 2014b). For example, groups could be constructed based on race and performance scores computed for each group.

<sup>3</sup>Minnesota Laws 2014, Chapter 312, Article 23, Section 10.

<sup>4</sup>The legislation also calls for MDH to assess the Quality Reporting System risk adjustment methodology by January 2016. The quality measure stratification plan will inform the risk adjustment assessment.

<sup>5</sup>Minnesota Hospital Association (MHA) [www.mnhospitals.org](http://www.mnhospitals.org).

<sup>6</sup>Stratis Health, [www.stratishealth.org](http://www.stratishealth.org).

report results to increase accountability and improve care, the Minnesota Council of Health Plans established the Minnesota Community Measurement Project in 2002.<sup>7</sup> The project issued its first performance report on Optimal Diabetes Care in 2003, and its first report on medical group performance in 2004.

In 2005, Minnesota health plans and the Minnesota Medical Association (MMA) established Minnesota Community Measurement (MNCM) to better coordinate quality measurement activities including data collection, data validation, and measure development. Over the years, more medical groups submitted quality measure data to MNCM, and health care organizations—including medical groups, health plans, state agencies, and business collaboratives—increasingly used the quality measures for quality improvement activities and pay-for-performance programs.

## Minnesota Statewide Quality Reporting and Measurement System

Enacted in 2008, Minnesota's Health Reform Law requires the Commissioner of Health to establish a standardized set of quality measures for health care providers across the state.<sup>8</sup> The goal is to create a more uniform approach to quality measurement to enhance market transparency and drive health care quality improvement through an evolving measurement and reporting strategy. This standardized quality measure set, which built on earlier voluntary efforts and made data submission by providers mandatory, is called the Minnesota Statewide Quality Reporting and Measurement System (Quality Reporting System).<sup>9</sup> Physician clinics and hospitals are required to report quality measures annually.<sup>10</sup>

At this point, more than 1,200 clinics report on 12 quality metrics; similarly, 133 hospitals report on a number of hospital measures (Appendix B).

- Payers, including the Department of Human Services (DHS), may use these statewide measures for performance-based contracting or pay for performance initiatives, including through the Bridges to Excellence program, the MDH Quality Incentive Payment System, and DHS Integrated Health Partnerships program.
- Consumers may use available data, including data reported publicly by MNCM, to choose a clinic, and providers may use their data for quality improvement initiatives and benchmarking.

MDH updates the measure set annually, following a process of seeking public comments and recommendations from the community, by issuing an updated administrative Rule. The Rule describes specific data elements that providers are required to submit to MDH for each measure.

To cover essential roles such as data collection, measurement development and maintenance, provider education and making recommendations for changes to the measurement set, MDH contracts with a

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<sup>7</sup>Minnesota Community Measurement (MNCM), [mncm.org](http://mncm.org).

<sup>8</sup>Minnesota Statutes, Section 62U.02.

<sup>9</sup>Minnesota Administrative Rules, Chapter 4654.

<sup>10</sup>The Commissioner of Health is also required to establish a system for risk adjusting quality measures, issue annual reports, and develop a system of quality incentive payments. Statewide data collection began in 2010 on 2009 dates of service, and 2015 marks the sixth year of statewide data collection. The Commissioner of Management and Budget is directed to implement the system for the State Employee Group Insurance Program, and the Commissioner of Human Services is directed to do the same for all enrollees in state health care programs.

consortium of vendors that is led by MNCM and includes MHA and Stratis Health.<sup>11</sup> Outside of its role as lead vendor for the Quality Reporting System, MNCM also acts as an independent quality measurement organization, collecting data from providers on metrics outside of the mandated measures on a voluntary basis. Additionally, MNCM publicly reports a range of quality and cost data on Minnesota clinics and hospitals on its HealthScores website.<sup>12</sup>

## Current Quality Reporting System Data

The Quality Reporting System is not a unified data set. Rather, it includes clinic and hospital quality measures that are submitted via different mechanisms from different sources. As a result, an implementation plan for stratifying quality measures based on socio-demographic factors cannot be one-size-fits-all, but rather must recognize the different submission processes, data standards and capabilities that are currently in place for hospitals and clinics. The measures in the Quality Reporting System have three primary data sources:

- (1) Providers' patient medical records, which are increasingly stored in an electronic health record (EHR) system;
- (2) Patient experience of care surveys that providers dispense to patients through survey vendors; and
- (3) Administrative claims, which are stored in a practice management system and are also referred to as "discharge data" in the hospital setting.

As previously noted, data submission requirements are detailed in the Quality Rule, which lists specific measures and data elements that providers are required to submit to MDH or its designee (currently MNCM for clinic measures) annually. MDH is directed to use data that are submitted to meet the requirements of the Rule for analysis only as allowed by law and Rule.

The Appendices to Minnesota Administrative Rules, Chapter 4654 (aka "the Quality Rule") require providers to submit data on age, gender, primary payer and zip code for all measures. However, MDH's access to that data from MNCM has been inconsistent. MDH's ability to stratify quality measures by socio-demographic factors is dependent upon what information it can obtain and at what level of granularity—case level, summary level, or community level (Appendix C). Recommendations in this report are based on the assumption that clinic-level data that are submitted to meet the requirements of the Quality Rule are consistently available to the Department to meet its statutory obligations; data that are submitted outside of the Rule, for instance voluntarily and in support of initiatives that are unique to MNCM, are assumed to not be available to the Department to meet its statutory obligations.

Appendix D details the additional variables associated with health outcomes that could be reported on as part of the implementation of stratifying health care quality measures. These variables include insurance status, race and ethnicity, language, country of origin, sexual orientation, neighborhood and community characteristics (which includes income), employment, education, and financial resource strain. With exception of the data element identifying the primary payer, none of these variables are currently required to be reported as part of the Quality Reporting System.

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<sup>11</sup>To identify qualified vendors, MDH conducted two competitive procurement processes in 2008 and 2013.

<sup>12</sup>Minnesota HealthScores, [www.mnhealthscores.org](http://www.mnhealthscores.org).

With those limitations in mind, this report lays out the necessary considerations in any, “implementation plan for stratifying measures based on disability, race, ethnicity, language, and other socio-demographic factors that are correlated with health disparities and impact performance on quality measures.”<sup>13</sup>

## Study Approach

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To develop a quality measure stratification plan as directed by the Legislature, MDH investigated the following questions:

- What is the perspective of members from diverse communities about sharing socio-demographic factors with health care providers and seeing the information used?
- What socio-demographic factors do Minnesota clinics and hospitals collect for state and federal quality measurement and reporting initiatives?
- What other socio-demographic factors and data sources could be used to stratify Quality Reporting System measures, and what are the associated benefits and challenges?
- What options should Minnesota consider in stratifying quality measures using socio-demographic factors, and what are the associated benefits, challenges, costs, and timelines?

To answer these questions and develop the quality measure stratification plan, MDH performed the following tasks:

- *Analysis of quality measure data.* MDH analyzed its aggregated Quality Reporting System data.
- *Literature review.* MDH reviewed research reports and peer reviewed literature related to the capture, collection, and stratification of socio-demographic information for purposes of assessing quality performance and health disparities.
- *Stakeholder input.* MDH worked with a contractor, Voices for Racial Justice,<sup>14</sup> to obtain input from community representatives using culturally appropriate methods. Voices for Racial Justice also partnered with the Minnesota Association of Community Health Centers (MNACHC) to interview representatives of safety net clinics.<sup>15</sup> MDH consulted with the Minnesota Administrative Uniformity Committee and Minnesota e-Health Initiative Advisory Committee and Standards and Operability Workgroup,<sup>16</sup> and conducted interviews with representatives of MNCM, Minnesota Council of Health Plans (MCHP), MHA, MMA, and Stratis Health. The recommendations included in this report do not necessarily represent a consensus view reached among the communities and organizations that provided input.

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<sup>13</sup>Minnesota Laws 2014, Chapter 312, Article 23, Section 10.

<sup>14</sup>Voices for Racial Justice is a Minnesota organization, previously operating under the name Organizing Apprenticeship Project, that works with communities of color and American Indians on issues of equity and inclusiveness.

<sup>15</sup>Minnesota Association of Community Health Centers (MNACHC) is a non-profit membership organization of Minnesota’s Federally Qualified Health Centers (FQHC). It works on behalf of its members and their patients to promote the cost-effective delivery of affordable, quality primary health care services, with a special emphasis on meeting the needs of low income and medically underserved populations, [www.mnachc.org](http://www.mnachc.org). Safety net clinics serve low-income, diverse and disadvantaged populations; they provide health care services to individuals and their families regardless of a patient’s ability to pay.

<sup>16</sup>For more information on Minnesota’s e-Health Initiative, please visit [www.health.state.mn.us/e-health/index.html](http://www.health.state.mn.us/e-health/index.html).

# Findings

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## I. Community Perspectives

### Interviews

While much of this report focuses on the steps that providers, payers, and the State could or should take to move towards stratifying quality measures by 2017 based on race, ethnicity, language, disability, and other relevant socio-demographic factors, the patient's voice and perspective is equally, if not more, important to this conversation. If patients do not feel comfortable providing this information about themselves—at the point of care, at health insurance enrollment, or in other ways—data collection will be incomplete and analysis biased or otherwise of potential limited value.

To ensure that the patient and community voice was fully considered as part of this report, MDH worked with an organization called Voices for Racial Justice to conduct key informant interviews around the state with members from diverse communities using authentic engagement methods (Appendix E). VRJ was careful in selecting community members that could provide generalizable feedback from a range of perspectives. Still, the views shared with interviewers may not be exhaustively representative of all community perspectives.

Voices for Racial Justice interviewed 85 members of diverse communities disproportionately impacted by health inequities which included representation from the following communities: American Indian/Native American, Black-African American, African Immigrant, Asian Pacific Islander, Latino/Hispanic, Lesbian Gay Bisexual Transgender Queer/Questioning (LGBTQ) Two-Spirit<sup>17</sup>, and people with disabilities (VRJ, 2014). To gather a broad set of perspectives, Voices for Racial Justice encouraged interviewers to diversify their interviews by engaging individuals with varying socio-demographic factors (Appendix F, Table F-1).

### Information Sharing

Effective socio-demographic information collection and quality measure stratification depends on patients' willingness to provide information to their care providers. Most of the interviewed community members were willing to share information with providers about disability, race, ethnicity, language, and country of origin. Persons who identified as Latino and Hispanic showed some hesitancy in comparison to those who identified as some other race and ethnicity; some of these interviewees stated that they would be reluctant to provide race and ethnicity information due to their immigration status and fear of deportation (Appendix F, Table F-2).

Eighty percent of interviewees found the race, ethnicity, and language categories to be very good, good, or acceptable. Interviewees were somewhat less amenable to sharing information about sexual orientation and income with health care providers. Some interviewees who identified as LGBTQ-Two Spirit expressed a fear of being mistreated by the health care system if they disclosed their sexual orientation. With respect to income, some interviewees questioned why the health care system would need that information to care for them.

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<sup>17</sup>Two-Spirit is a term that can be applied to Native Americans who are Gay, Bisexual, Lesbian, or Transgender. Two-Spirit is generally felt to be the more culturally sensitive and accurate term when referring to Native LGBTQ individuals.

## How, Whom, When

Interviewed community members varied in their opinions of how socio-demographic information should be requested, by whom, and when (Appendix F, Table F-3).

- Overall, 35 percent preferred that socio-demographic information be requested verbally. The second most preferred option expressed was to have information requested in written form (26 percent). Using electronic means for socio-demographic information collection showed more of a divide between age groups than other socio-demographic factors with interviewees aged 35 years or younger preferring electronic methods.
- Most interviewees expressed a preference regarding who should ask for socio-demographic information—69 percent preferred it be collected by a health care worker (provider, medical assistant, or nurse) rather than the front desk staff (21 percent).
- Responding to at which point socio-demographic information should be collected, interviewees were split between collecting the information while in the exam room (40 percent) or at check-in (39 percent). LGBTQ-Two Spirit individuals and Latinos favored collecting information while in exam rooms. Only a small percentage of interviewees communicated that socio-demographic information should be collected by phone.

## Building Trust

Interviews with community members underscored the importance of building trust between patients and the health care system, and increasing patient understanding of why providers collect socio-demographic information, and how they protect and use it. Most interviewees did not know how requested socio-demographic information would be used. Most community members agreed that it was important to know:

- How their socio-demographic information will be used (93 percent);
- Who will have access to it (97 percent);
- Data will be shared with researchers in diverse communities (87 percent); and
- Patient privacy will be protected by ensuring complete de-identification of data.

Most interviewees agreed it would be helpful for health care staff to be trained how to ask patients for socio-demographic information in a culturally appropriate manner. Most interviewees agreed it would be helpful for communities to receive education about how the collection of socio-demographic information can improve the health of the community, because then community members could become more actively involved in planning, supporting, and implementing new information collection methods and building trust with the health care system in their communities. Furthermore, most interviewees agreed that members of the communities experiencing inequities need to be authentically engaged in conversations with health care and government leaders to plan and implement next steps around the collection and reporting of socio-demographic factors which may foster greater trust between communities and the health care system. Community stakeholders asserted that the communities themselves are best situated to decide what types of data and analyses are most needed.

## Community Recommendations

Based on the content of the community interviews, Voices for Racial Justice made 14 recommendations about collecting and using patient socio-demographic information for purposes of stratifying quality data by 2017; raising awareness of social determinants of health, structural racism, and discrimination; and identifying and eliminating health disparities (Appendix G):

- Developing data collection methods in collaboration with the community to ensure that they are culturally appropriate;
- Communicating with patients about the purpose, use, and protection of patient socio-demographic information, including by providing examples of the use;
- Providing health equity data to communities so they can be used for health improvement and advocacy; and
- Authentically engaging and partnering with communities impacted by health disparities throughout the entire process of implementing and administering changes to the Quality Reporting System related to race, ethnicity, language, country of origin, and other socio-demographic factors.

## Recommendations #1-3

Recommendation 1: In preparation for stratification in 2017, MDH should work with vendors and stakeholders to develop a statewide education campaign for: (1) providers to learn about best data collection practices, legal underpinnings for collection of data, use cases of data and how to relate the purpose of data collection to community members; and (2) for community members to create patient buy-in for collection of key socio-demographic factors. The education campaign should be conducted in close collaboration with diverse communities and patient populations using authentic engagement methods.

Recommendation 2: To empower communities to play a strong role in reducing health disparities, MDH should prepare de-identified summary data files and data analyses of quality performance measures stratified by key socio-demographic variables for use by community researchers.

Recommendation 3: To the extent that case-level data are not obtainable for this work, MDH should use community variables as stratifiers, or publicly available data at geographic levels of aggregation. This work should begin prior to 2017 with data stratified with the help of community variables and be extended after additional de-identified patient-level data are available in 2017 reports on stratified quality measures.

## II. Clinic Reporting of Socio-demographic Factors for EHR-populated Measures

As noted earlier, quality measurement of health care services in Minnesota is largely performed for clinics using three types of data—patient medical record, patient experience of care survey, and administrative transactions. In this section, we will present findings from our analysis about pathways to greater stratification of quality information for clinics using socio-demographic factors that are stored in providers’ patient medical records (i.e., in EHRs) and that clinics report for quality measurement initiatives.

### Age, Gender, Zip Code, and Primary Payer

Most Minnesota clinics collect basic socio-demographic information, including patient age, gender, residential zip code, and primary payer in the course of delivering care to patients; these variables are required to be submitted by all clinics pursuant to the Quality Rule for the purposes of measure stratification and risk adjustment. This data flows through MDH’s vendor, MNCM, as part of quality measure data submission.

However, in the process of aggregating data at the clinic level, only primary payer information for most of the measures is provided to MDH; patient age, gender, and zip code is not consistently provided to MDH. As a result, MDH's ability to link these measures to other data sets like the American Community Survey or to publicly report on variations based on these variables is limited.

MDH's contract with MNCM does give medical groups the option to voluntarily share case-level data with MDH. For medical groups that opt to share case-level information (about 60 percent of clinics), MNCM provides MDH with age, gender, and residential zip code information, but not payer information, which can act as a proxy for income.<sup>18</sup> Examples of analyses that could be conducted include identifying quality performance differences between asthmatic patients of varying ages, between diabetic patients in different geographies, or between patients with cardiovascular diseases who are served by different payers.

## Recommendation #4

To accomplish the goal of stratifying outpatient quality measures by 2017, MDH should conduct and publish an analysis of variations in quality of care using currently-collected age, gender, zip code, and primary payer data linked with community variables by August 2017.

## Community Variables

Community variables, or variables that are collected for populations in certain geographic boundaries—such as the zip code, census tract, or neighborhood level—can also be used to stratify quality measures. They can at times serve as a proxy for individual data or as contextual variables that characterize the environment in which the patient lives (NQF, 2014b). Common community variables used to assess equity include income or the poverty rate, geographic distance to pharmacies, availability of public transportation, types and availability of food outlets, neighbor and social support infrastructure, and availability of parks and recreation areas. In rural communities, this includes the geographic distance to healthcare providers.

These community characteristics could, in some cases, be as or even more important than individual socio-demographic factors in terms of accounting for access to economic and social infrastructure, and health care services. Nationally, a number of organizations are moving towards use of community variables to explore variations in care; the Institute of Medicine (IOM) recommended the inclusion of geocoded residential address and census tract median household income as demographic variables in Meaningful Use Stage 3 requirements (IOM, 2014).

If patient zip code was consistently provided to MDH by its vendor as part of the Quality Reporting System, MDH could obtain community variables through U.S. Census data (without imposing any new reporting burden on providers), link them to quality measures, and stratify results with no additional data collection required.

In conclusion, variables such as age, gender, zip code, and primary payer have the potential to help explain variations in quality of care across regions and populations. MDH could accomplish some of the goals of socio-demographic analysis with those aggregated variables, although the development of risk adjustment methodologies for quality of care reporting will always require case-level data. Minimizing

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<sup>18</sup>Clinics do not submit information on patient name, street address, or social security number.

the collection of new data elements would limit new costs and administrative complexity to providers, especially those in smaller clinical settings. But as previously noted, collection of this data is currently inconsistent, voluntary and limited to a subset of the population; reliance on community variables would also limit how the detail at which disparities in quality performance can be understood.

## Recommendation #5

MDH should convene stakeholders from diverse communities and population measurement experts to identify and refine the selection of community variables for stratification analysis and report of quality measures. MDH should develop a summary report beginning in August 2017 with calendar year 2016 service date quality data.

## Race, Ethnicity, Language, and Country of Origin

Data suggest most Minnesota clinics already capture patient race, ethnicity, language, and country of origin information in their EHR systems for a variety of reasons:

- To meet federal requirements to demonstrate that these systems are “meaningfully used” for clinical support and information exchange;
- To participate in MNMCM’s voluntary effort to collect and report data on race, ethnicity, language, and country of origin;
- For Federally Qualified Health Centers (FQHC) to meet certification requirements of the U.S. Department of Health and Human Services Health Resources and Services Administration; and ultimately,
- To have the measurement tools through which to explore how to better serve their diverse patients by identifying disparities in outcomes, processes of care, or patient experience.

Some improvements in EHR capabilities and processes may be necessary to capture more than one race per patient in EHRs, increase the number of clinics that capture the data, and align with likely upcoming federal changes (Stratis, 2014).

## Federal Requirements about Meaningful EHR Use and FQHC Certification

Many Minnesota clinics are already capturing patient race, ethnicity, and language, in part, to meet federal health information technology (called “Meaningful Use”) requirements and to be eligible for federal incentive payments starting in 2015.<sup>19</sup> These requirements are aligned with the federal Office of Management and Budget (OMB) standards for race and ethnicity, and Library of Congress standards for language.<sup>20, 21</sup>

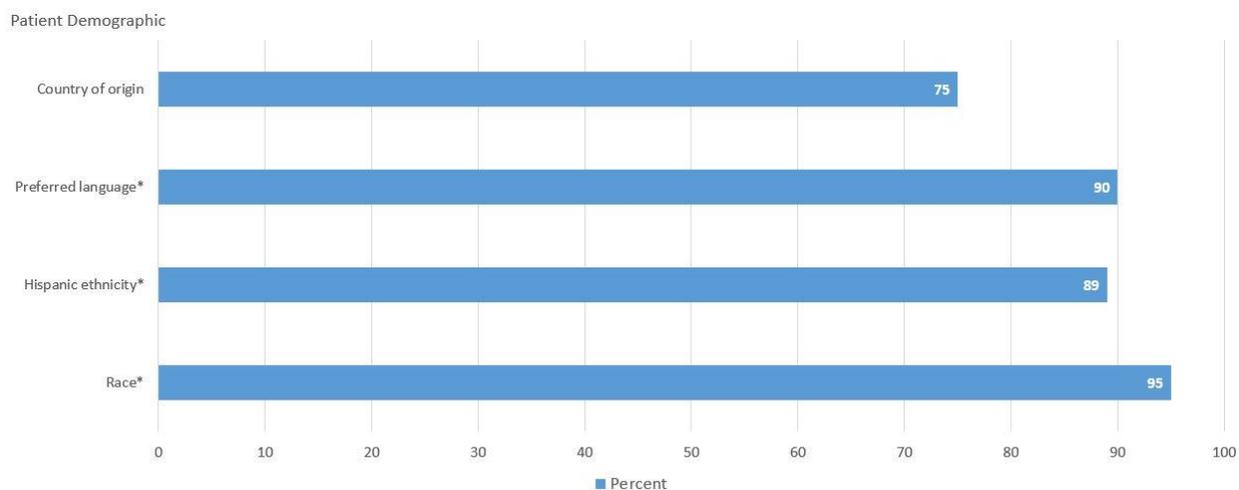
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<sup>19</sup>In 2009, Congress passed the Health Information Technology for Economic and Clinical Health Act (HITECH Act). The HITECH Act authorized new financial incentives through the meaningful use incentive program involving Medicaid and Medicare programs. The objective is to ensure that the adoption and use of health IT contributes to a more efficient, effective and safe health care system that achieves improved health outcomes.

<sup>20</sup>OMB race classifications include American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, and White, and ethnicity classifications include Hispanic or Latino, and not Hispanic or Latino. Under those standards, self-reporting or self-identification by individuals is strongly preferred, and persons may identify more than one race. The Office of Management and Budget Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity, Statistical Policy Directive No. 15, as revised, October 30, 1997. Available at [www.whitehouse.gov/omb/fedreg\\_1997standards](http://www.whitehouse.gov/omb/fedreg_1997standards).

MDH’s Health Information Technology (HIT) survey found that in 2014, most responding clinics that had EHRs (92.6 percent) were capturing race, Hispanic ethnicity, preferred language, and country of origin information on 80 percent or more of their patients (Figure 1). Only 66 percent of those clinics were able to capture and report more than one race for patients in their EHRs. Almost half of the clinics that capture ethnicity in their EHRs are also able to capture and report granular ethnicity (OHIT, 2014).

**Figure 1: Minnesota Clinics with EHRs Capturing Demographic Information on 80% or More of Their Patients, 2014**



\*Indicates Meaningful Use Stage 2 demographic (i.e., more than 80 percent of patients have race, ethnicity, and language recorded as structured data).

There were 1,118 clinics that reported having an EHR.

Source: MDH, Office of Health Information Technology, 2014 Minnesota Health Information Technology Ambulatory Clinics Survey.

The federal government is expected to issue Meaningful Use Stage 3 requirements during 2015 and as a result, providers in Minnesota may collect more granular information on patient race and ethnicity through their EHRs for reporting during 2017. In 2014, the IOM recommended that Meaningful Use Stage 3 requirements for the collection of patient race and ethnicity information align with U.S. Census standards that provide more comprehensive categories of race and a more specific description of ethnicity (IOM, 2014).<sup>22, 23</sup>

<sup>21</sup>There are more than 200 languages included in the specified Library of Congress language standards. Library of Congress, ISO 639-2 alpha-3 codes limited to those that also have a corresponding alpha-2 code in ISO 639-1. Available at [www.loc.gov/standards/iso639-2/langhome.html](http://www.loc.gov/standards/iso639-2/langhome.html).

<sup>22</sup>U.S. Census race categories include: White; Black, African American, or Negro; American Indian or Alaskan Native (with fill in option); Asian Indian; Chinese; Filipino; Japanese; Korean; Vietnamese; Native Hawaiian; Guamanian or Chamorro; Samoan; Other Pacific Islander (with fill in option); other Asian (with fill in option); and Some other race (with fill in option). U.S. Census ethnicity categories include: Mexican, Mexican American, Chicano; Puerto Rican; Cuban; and another Hispanic, Latino, or Spanish origin (with fill in option). Under these standards, self-reporting or self-identification by individuals is strongly preferred, and persons may identify more than one race and ethnicity.

The U.S. Department of Health and Human Services Health Resources and Services Administration Bureau of Primary Health Care requires FQHCs to collect information on patient race, ethnicity, language, age, gender, zip code, primary health insurer (BPHC, 2014).<sup>24</sup> The Health Resources and Services Administration also requires FQHCs to report low birth weight, controlled hypertension, and controlled diabetes intermediate outcome measures by race and ethnicity to provide information on the extent to which FQHCs help to reduce health disparities. Measure results aggregated at the state level are publicly available for Minnesota FQHCs, but individual FQHC results are not publicly reported.<sup>25</sup>

## Quality Measurement

MNCM has been voluntarily collecting race, Hispanic ethnicity, preferred language, and country of origin information from medical groups since 2010 (MNCM, 2010), building on earlier voluntary efforts begun by a number of medical groups as early as 2006.

MNCM encourages medical groups to submit this information for all measures that are populated with data from the patient medical record and provides a variety of resources, including a data collection handbook and a technical guide, to support providers in submitting data (MNCM, 2010). MNCM uses the OMB race and ethnicity standards. Additionally, MNCM established a minimum but broad list of language categories from which patients can choose based on collaborative work from the Minnesota Immigrant Task Force (MNCM, 2010). MNCM also established a minimum list of countries to present to patients.

MNCM's best practice parameters for medical groups' collection of race, Hispanic ethnicity, preferred language, and country of origin information entails that:

- (1) Patients self-report information; and
- (2) The medical group's form or EHR is able to collect and report more than one race if reported by the patient, rather than using a "multi-racial" category.

According to MNCM, during 2014, more than 70 percent of medical groups that voluntarily submitted this socio-demographic information to MNCM followed best practices (MNCM, 2015). It is possible that other medical groups are collecting race, Hispanic ethnicity, and preferred language information and either choose to not submit the data voluntarily or lack the EHR functionality to capture more than one race. Information about the characteristics of medical groups that did and did not meet MNCM's best practices, and the number of reporting and non-reporting clinics is not available publicly. According to MNCM, most of the remaining medical groups have indicated that they have plans in place to build this functionality into their EHRs in the future.

MNCM issued, for the first time, a report in January 2015 that stratified five quality measures by race, Hispanic ethnicity, preferred language, and country of origin information statewide and by geographic

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<sup>23</sup>Consistent with recommendations of the Racial/Ethnic Health Data Workgroup that the Minnesota Departments of Health and Human Services convened in 2010, race and ethnicity should be collected using more detailed categories than the OMB standards so that data would be more useful in understanding health issues and needs for particular patient groups (MDH and DHS, 2011).

<sup>24</sup>The UDS tracks a variety of information, including patient demographics, services provided, staffing, clinical indicators, utilization rates, costs, and revenues.

<sup>25</sup>Measure results found at Department of Health and Human Services, Health Resources and Services Administration (HRSA), Bureau of Primary Health Care (BPHC), [bphc.hrsa.gov/healthcenterdatastatistics/index.html](http://bphc.hrsa.gov/healthcenterdatastatistics/index.html).

region (MNCM, 2015). MNCM did not publicly report stratified results by medical group, but it may do so in the future. Clinic data may not meet minimum cell size requirements, even with full reporting. MNCM reported that its future plans include updating the report annually, evaluating and exploring reporting results by medical group, using socio-demographic factors for risk adjustment of its publicly displayed data, conducting other analyses, and collecting other socio-demographic information. MNCM indicated interest in partnering with other organizations—including MDH—to promote collaborative and integrated efforts and evidence-based programs to reduce health disparities.

In conclusion, many Minnesota providers capture patient race, ethnicity, and language information in their EHRs to meet federal requirements related to using electronic records in meaningful ways and to measure quality of care for certain conditions. However, technical improvements are needed to meet best practices standards related to capturing more than one race per patient in EHRs.

The majority of Minnesota clinics voluntarily report race, ethnicity, language and country of origin data to MNCM. Data may be publicly reported annually at the medical group level or at the clinic level, but publication at that level of granularity would likely depend on having sufficient numbers of patients in the population groups being compared.

## Recommendation #6

To operationalize the Legislature’s directive to stratify quality measures by these variables by 2017, the Legislature could consider two distinct approaches. Under either approach, data collection standards should be aligned with federal requirements for meaningful use of EHRs that will be released in 2015, and developed in close consultation with community partners.

**Option 1:** Minnesota law (section 62U.02) and Rule (Chapter 4654) could be modified to require clinics to submit race, ethnicity, language, and country of origin data to MDH as part of the Quality Reporting System beginning as soon as 2016. Assuming that MDH has access to all data that is submitted pursuant to the Quality Rule to meet this new requirement, including de-identified case-level data, MDH could stratify and produce analyses of quality measures based on these factors, and use data to develop risk adjustment approaches that include these variables pursuant to legislative timelines. Aggregated summary information would be available to other state health care quality measurement and improvement programs, as well as consumers, advocates and community organizations. There would be vendor costs associated with producing data and reimbursing for the economic value the data represents.

**Option 2:** Minnesota clinics could continue to voluntarily submit race, ethnicity, language and country of origin data to MNCM as they have been doing since 2010. MNCM has indicated that it plans to update its ‘Health Equity of Care’ public report regularly, and could use submitted data to develop approaches to risk adjustment that include these variables. If this option is selected, MDH would be unable to perform stratification of clinic quality measures by these variables, to develop risk adjustment methodologies, or to make aggregate data available to community organizations or others. There would be no additional costs, and no additional data collection burden associated with this option.

## III. Hospital Reporting of Socio-demographic Factors for EHR-populated Measures

Like clinics, Minnesota hospitals are already capturing patient race, ethnicity, and language information to a significant extent to meet Meaningful Use requirements and be eligible for federal incentive

payments. During 2013, of the 139 Minnesota hospitals that reported having EHRs, 97 percent recorded patient race and ethnicity information, and 96 percent recorded preferred language.<sup>26</sup>

Because nearly all EHR-based measures in the Minnesota Quality Reporting System are highly aligned with federal measurement specifications and rely on submission of the data to federal agencies, MDH has little control over the content of data submission and relies on summary data reported by federal agencies. Although key federal programs like the CMS Hospital Inpatient and Outpatient Quality Reporting Programs require hospitals to submit race and ethnicity information when reporting quality measures with data populated by EHRs, this data is not available publicly and it is not clear whether CMS will release patient socio-demographic information upon request (CMS, n.d.-a; CMS, n.d.-b). For hospitals to report patient race, ethnicity, language, and other socio-demographic factors to MDH for EHR-populated measures, Minnesota could request this information from CMS, or it would need to develop a parallel reporting system and supporting information which would impose additional administrative reporting burden.

With growing federal and national interest in using socio-demographic factors to stratify and risk adjust quality measures and to address disparities in health care, it is possible that data on these factors may become publicly available in the coming years. For example, the NQF “Expert Panel on Risk Adjustment for Socio-demographic Factors” (2014b) recommended that:

- CMS and other producers of performance reporting should make stratified data easily available to interested parties, such as consumer advocates, researchers, health plans, and providers;
- Doing so could serve a dual purpose of providing finer grained data to interested parties and for assessing and addressing healthcare disparities.
- NQF and others such as CMS, Office of the National Coordinator (ONC) for Health Information Technology, and AHRQ should develop strategies to identify a standard set of socio-demographic variables (patient and community-level) to be collected and made available for performance measurement and identifying disparities.

Based on the Expert Panel’s recommendations NQF’s Board approved a trial that will assess the impact and implications of risk adjusting relevant quality measures for socio-demographic factors. CMS has signaled an interest participating in implementing this trial (NQF, 2014a), but a timeline for results is currently unknown.

## Recommendations #7-8

Recommendation 7: To assess whether data can be made available to meet the Legislature’s direction to stratify hospital-based quality measures by 2017, MDH should work with Stratis Health, MHA, and the Hospital Quality Reporting and Steering Committee to explore obtaining race and ethnicity information from CMS for applicable Quality Reporting System measures with the goal of reporting back on the results of that collaboration by January 15, 2017.

Recommendation 8: Additionally, MDH should monitor and report back to the Legislature experiences with the National Quality Forum’s trial period in which NQF will assess the impact and implications of risk adjusting relevant quality measures for socio-demographic factors.

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<sup>26</sup>Minnesota HIT Hospital Survey, 2013. Results for the 2014 Minnesota HIT Hospital Survey are expected in March 2015. These results will include Meaningful Use Stage 2 metrics such as the rate of hospitals capturing race, ethnicity, and language information for 80 percent or more of their patients, and hospitals’ ability to capture more than one race per patient.

## IV. Patient Experience of Care Surveys and Socio-demographic Factors

The clinic and hospital patient experience of care surveys that are in the Quality Reporting System are developed and maintained by federal agencies—AHRQ and CMS respectively—which also store the results. These surveys ask respondents for their age, gender, education level, race, and ethnicity. Clinics and hospitals can choose whether to receive patient socio-demographic information from their survey vendors.

MDH requires clinics to conduct the patient experience of care survey every other year, but does not require clinics to report patient socio-demographic information as part of their submission. Interested parties may submit applications to obtain patient experience data for specific analysis projects to the federal Consumer Assessment of Healthcare Providers and Systems (CAHPS) Database Management Committee, a division of the Agency for Healthcare Research and Quality (AHRQ) for review and approval.

MDH obtains patient experience of care data for Minnesota hospitals through CMS Hospital Compare, which does not include patient socio-demographic information in the data files. It is not clear whether CMS will release patient socio-demographic information upon request for specific studies.

### Recommendation #9

To meet the Legislature’s directive to stratify quality measures based on socio-demographic variables by 2017, MDH should obtain de-identified Minnesota patient experience survey data from CAHPS to assess the volume of socio-demographic data collected through this survey and identify methods for stratifying patient experience metrics by the available and appropriate socio-demographic variables. MDH should report on the results of this study and obtain stakeholder feedback to inform potential changes to Minnesota Rule (Chapter 4654) by January 15, 2017.

If MDH determines, in consultation with stakeholders, that it is beneficial to stratify patient experience of care measures based on socio-demographic variables, Minnesota law (section 62U.02) and Rule (Chapter 4654) would need to be modified to access or analyze patient experience of care measures as part of the Quality Reporting System.

## V. Administrative Transactions and Socio-demographic Factors

Alongside the clinical information that is collected through electronic health records, providers and payers also collect and report business (administrative) data for billing and reimbursement purposes. Administrative transactions include the submission and payment of claims for services provided, and information about an individual’s eligibility for coverage. This system is national in scope and electronic versions of the transactions are regulated through rules adopted pursuant to the federal Health Insurance

Portability and Accountability Act of 1996 (HIPAA).<sup>27</sup> CMS administers and enforces HIPAA administrative simplification rules.

In parallel with federal requirements, Minnesota is also dedicated to reducing health care administrative costs and burdens through the state's Health Care Administrative Simplification Act.<sup>28</sup> This Legislation was enacted to bring about greater standardization and electronic exchange of health care administrative transactions, and to reduce administrative costs and burden. MDH consults with the Minnesota Administrative Uniformity Committee (AUC)—a large, voluntary stakeholder organization that is comprised of representatives of health plans and provider organizations – in implementing and administering the Administrative Simplification Act.

## Limited Capabilities of Administrative Transactions to Collect Socio-demographic Factors

Discussions with experts in Minnesota revealed three potential pathways for the collection of socio-demographic factors through administrative transactions:

- (1) Addition of these factors by providers to supplement the standard administrative transaction records;
- (2) Addition of these factors by payers to insurance policy enrollment records for later inclusion in administrative transaction records; or
- (3) Statistical linking of patient medical record with health care claims data through which variables from the EHR can be “attached” to the transaction records.

Electronic eligibility and claims administrative transactions—adopted under HIPAA and State law—include the collection and reporting of patient age, gender, zip code, payer, and disability status (short term, long term, permanent, no disability), but do not currently allow for the collection and reporting of race, ethnicity, and language. There is no indication that national organizations are considering standardizing the exchange of race, ethnicity, and language information through standard HIPAA transactions.

The health plan enrollment transaction could be used to collect the narrow range of patient socio-demographic information above; however, there are a number of limitations with this method. Employers are not subject to HIPAA administrative simplification rules and do not routinely submit their employees' health insurance enrollment data to insurers via the HIPAA standard electronic enrollment transaction. Additionally, the requirements in the standard enrollment transaction implementation guide specify that socio-demographic data can be exchanged only when there is a corresponding provision to do so in contracts between employers and insurers. For a variety of reasons—including that employers are not required by law to provide enrollment data via the standard HIPAA enrollment transaction—such contracts with the necessary data exchange provisions may often be absent.

Even in situations where the enrollment transaction may be used to transmit insurance enrollment information and contains the necessary agreed upon contract terms, employers may be reluctant for a number of reasons to gather personal data such as race or disability from their employees. This reluctance may arise for several reasons from concerns about the time and effort involved, to discomfort with

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<sup>27</sup>The Health Insurance Portability and Accountability Act of 1996 (HIPAA) P.L. No. 104-191, 110 Stat. 1938 (1996).

<sup>28</sup>Minnesota Statutes, Section 62J.50 - 62J.63.

collecting and recording such personal information, to concerns about any potential legal liability for improper access to or use of the data.

## Quality Measurement

Provider organizations and health plans use administrative claims data to calculate quality measures, and some of these clinic and hospital measures are in the Quality Reporting System. These measures are developed and maintained by national and federal organizations, and they do not require the inclusion of race, ethnicity, language, and other patient socio-demographic factors in their calculation.

MHA has been working with its members to collect race, ethnicity, and language information through claims transactions. For example, MHA conducted a study on collecting these variables for readmissions measures using claims transactions in conjunction with the Robert Wood Johnson Foundation and MNCM (MNCM, 2012). Although this study concluded in 2012, MHA has continued to ask its members to include race and ethnicity in their claims submissions to MHA. Currently, 87 hospitals submit these variables, and MHA expects that number to increase to 105 during 2015. Eventually, MHA intends to stratify some of the claims-based quality measures by race and ethnicity, although the timeline for this work is uncertain.

The Minnesota Council of Health Plans expressed concern about the accuracy and cost of patient socio-demographic data that could be transmitted through administrative transactions, and questioned whether other methods would be more effective.

## Recommendation #10

Relying on prior pilot studies by MHA, MDH should work in collaboration with the Minnesota Administrative Uniformity Committee, MHA, Stratis Health, the Hospital Quality Reporting and Steering Committee, and other stakeholder and measurement organizations to complete a study that assesses the implications and opportunities for stratifying claims-based measures in the Quality Reporting System and also the alternatives to populating administrative transaction records. MDH should report on the results of that collaboration by January 15, 2017.

## VI. Disability, Sexual Orientation, Gender Identity, and Other Socio-Demographic Factors (Clinics and Hospitals)

As part of the study, MDH reviewed evidence on the literature on the relationship between socio-demographic factors and health outcomes in order to identify relevant variables to consider for stratifying quality performance measures and better understanding health disparities in outcomes.

This section focuses on variables that have been identified by organizations such as the IOM and the NQF as variables most likely to have adequate strength in their association with health, appear useful for health care related decision-making by patients and providers, exist as reliable and valid measures, are feasible to be collected and are sensitive to patients' concern over privacy risk.

Among these factors, patient socio-demographic factors—such as disability, sexual orientation, gender identity, income, and employment—could be used to stratify health care quality measures; however, lack of a uniform disability definition, patient privacy and discrimination concerns, and perceived limited clinical usefulness of some of these factors impede standardized and statewide data collection and use.

## Disability

There is strong interest at the state and federal levels to improve care for people with disabilities, and to ensure that the care they receive is integrated and person-centered. As part of this work, Minnesota is implementing an “Olmstead Plan,” to provide services to individuals with disabilities in the most integrated setting appropriate to the individual and to set measurable improvement goals (Olmstead Sub-Cabinet, 2014).<sup>29</sup> MDH is a partner in this work, and a key component of the plan is to improve healthcare and healthy living for people with disabilities.

While there is a growing awareness of the need to address disparities in care for people with disabilities, the lack of a uniform and agreed-upon definition of disability has stood in the way of capturing this data element in a standard way in EHRs. For instance, the Federal Statutory Definitions of Disability lists 67 definitions used by various federal agencies (CESSI, 2003).

CMS and ONC have been contemplating how to capture disability in EHRs. CMS explored whether to mandate the collection of disability status as a demographic variable for Meaningful Use Stage 2 and decided not to because of the lack of an agreed-upon definition and associated data collection burden (CMS, 2012). Similarly, the IOM did not recommend disability measures for the social and behavioral domains of the next round of Meaningful Use requirements. ONC is seeking public comment on whether patient function and disability<sup>30</sup> should be included in EHRs and if so, whether the International Classification of Functioning, Disability and Health<sup>31</sup> should be included as a standard or whether other similar standards should be considered (ONC, 2015).

### Recommendation #11

While the current lack of standard definitions of disability for use in EHRs means that the goal of stratification by this factor in 2017 is not possible, MDH should submit a report to the Legislature in 2016 with recommendations on quality measurement and disability that are aligned with the Olmstead Plan and federal standards.

## Sexual Orientation, Gender Identity, and Other Socio-demographic Factors, Including Veteran Status, Housing, Income, and Employment

There is interest at local, state, and federal levels to capture sexual orientation and gender identity in EHR systems because of the health disparities faced by the LGBTQ population and lack of consistent data on this population’s health needs and concerns. For example, gay and bisexual men are more severely affected with HIV than any other group in the U.S.<sup>32</sup> LGBT youth are at greater risk for depression,

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<sup>29</sup>In the landmark civil rights case, *Olmstead v. L. C.*, 527 U.S. 581 (1999), the United States Supreme Court held that it is unlawful for governments to keep people with disabilities in segregated settings when they can be supported in the community. The Court and subsequent U.S. Department of Justice guidance encourages states to develop plans to increase integration.

<sup>30</sup>According to the World Health Organization, “functioning and disability” denote the positive and negative aspects of functioning from a biological, individual, and social perspective (WHO, 2013).

<sup>31</sup>The International Classification of Functioning, Disability and Health is the World Health Organization framework for measuring health and disability at both individual and population levels (WHO, 2013).

<sup>32</sup>[www.cdc.gov/hiv/risk/gender/msm/facts/index.html](http://www.cdc.gov/hiv/risk/gender/msm/facts/index.html).

substance use, and sexual behaviors that place them at risk for HIV and other sexually transmitted diseases (MDH, 2014, and unpublished analysis from the 2013 Minnesota Student Survey).<sup>33</sup>

CMS considered gender identity and sexual orientation for Meaningful Use Stage 2, but it did not include them because of lack of consensus in public comments on whether doing so would be useful, the degree of sensitivity of the information, and how it would be recorded. The IOM did not recommend sexual orientation and gender identity measures for Meaningful Use Stage 3 due to their limited usefulness and patient sensitivity (IOM, 2014). The IOM found that while knowledge of a person’s sexual orientation and sexual behavior can be useful for diagnosing and treating conditions that may be related to sexual orientation, for most conditions, knowing this information would not change the clinical approach. Because of this, the IOM decided that it would not be very useful to systematically include these measures in all EHRs.

Although sexual orientation and gender identity relate to health outcomes, MDH recommends not taking action at this point because of patient reticence to share such information due to privacy concerns and fear of discrimination, and perceived limited clinical usefulness of this information. MDH will continue to monitor local, state, and federal trends in collecting and using these socio-demographic variables.

Providers can collect other patient socio-demographic factors to tailor care to specified populations, and can stratify internal quality metrics based on this information. For example, Minnesota safety net providers collect patient socio-demographic information to improve care delivery for certain populations and to meet federal reporting requirements. One safety net provider in Minnesota conducts a lifestyle survey of its patients to assess their health risk factors and social needs. Using the survey data, this organization has developed and records housing stability and employment indicators for its patients. The provider organization and its partners use this information to target additional health care and human services. Additionally, HRSA requires FQHCs to collect information on patient income, migratory and seasonal agricultural worker status, homelessness, and veteran status in addition to age, gender, zip code, and primary health insurer, race, ethnicity, and language (BPHC, 2014).

Safety net clinic representatives interviewed for this report stated that they use patient socio-demographic information to:

- Review causal and correlated risk factors for readmissions and “no-show” rates;
- Identify racial disparities in provider quality measures and develop interventions;
- Review outcomes by geography using zip code and compare results against neighboring areas;
- Determine eligibility for sliding scale fee discounts;
- Identify socio-demographic factors of homeless patients; and
- Identify and meet language and interpreter needs of the patient population.

MDH is developing a Minnesota e-health framework in collaboration with the e-Health Initiative to advance health equity. This framework includes identifying and prioritizing the capture and use of socio-demographic factors—such as sexual orientation, gender identity, housing status, income, and employment—in the EHR. Major milestones and timelines are under development. MDH can also obtain socio-demographic information for factors such as income, employment, and housing stability by using community variables which were discussed in previous findings sections.

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<sup>33</sup>[www.cdc.gov/lgbthealth/youth.htm](http://www.cdc.gov/lgbthealth/youth.htm).

# Cost Considerations

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In addition to developing an implementation plan for stratification of quality measures by race, ethnicity, language, disability and other socio-demographic variables, the Legislature also directed MDH to estimate potential costs associated with the implementation plan. To implement the full set of recommendations in this report, MDH estimates fiscal costs in the amount of approximately \$2 million through calendar year 2018.

The expenditures are expected to cover two full time staff—a planner and a researcher—who would be responsible for analytic efforts, the preparation of reports, and facilitating project management. In aggregate, staffing costs and costs associated with contract management and support functions through 2018 are estimated to be \$787,000. To implement the recommendations, MDH anticipates also engaging between 4 and 6 contracts to perform advisory group facilitation functions, develop and implement education campaigns, collect data and play a role in summarizing available data. Contract activities through 2018 are estimated at \$1,133,000.

This estimate is associated with substantive uncertainties including:

- Any actual bill language may differ substantially from what is proposed in the implementation plan, which may result in lower or higher costs.
- A sizable part of the proposed work is technical in nature and subject to refinement through additional exploratory work. This makes developing precise estimates challenging.
- For some activities, the state assumes it would need to work with external vendors. Depending on the proposals the state receives, it may decide to perform the work in house, which may change the costs.
- MDH recommends working with a workgroup composed of members from diverse communities to advise on some aspects of the implementation plan. That group may recommend that MDH revise some of its assumptions related to implementation, leading to higher or lower costs over time.
- MDH assumes that there will no new costs for obtaining summary data by age, gender, zip code, payer, as those are already submitted under data collection Rules. To the extent that underlying cost structures would change, our estimates will be inaccurate.
- National developments, including the development of definitions or other standards that impact these recommendations, may occur on timelines different from those assumed here, or may occur in a way that makes some recommendations easier or more difficult to implement.
- Lastly, the implementation plan contains some alternative options that have varying implications for the overall costs. The overall project costs will vary based on the choice of the available options.

A table depicting the estimated costs for each recommendation is incorporated in the implementation plan on page 25. For this study we did not estimate ongoing costs for activities that would be pursued past 2018. If the Legislature chose to implement ongoing reporting functions, those would have ongoing costs associated with them.

# Conclusions

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This report summarized MDH's findings and recommendations for operationalizing the Legislature's 2014 directive to develop a plan for stratifying Quality Reporting System measures based on socio-demographic factors.

MDH analyzed quality measure data (providers' patient medical records, patient experience of care surveys, and administrative claims), performed a review of research reports and peer reviewed literature, and consulted with stakeholders (consumers, community and advocacy organizations representing diverse communities; health plans; providers; quality measurement organizations; and safety net providers that primarily serve communities and patient populations with health disparities).

After focusing on variables currently collected, variables of community interest (including disability, race, ethnicity, language, country of origin, sexual orientation and gender identity), and community variables (including income or the poverty rate, availability of public transportation, types and availability of food outlets), the proposed plan lays out multiple pathways to stratification that acknowledge both the differing sources of data that make up the Quality Reporting System and the current state of collection and reporting.

With the help of the proposed reports, Minnesota may develop a better understanding of disparities in quality performance among residents who represent diverse backgrounds and build the foundation with support of community researchers to identify areas of prioritization and focus to reduce inequity in care outcomes and patient experience.

Additionally, MDH will continue to learn more through its own research of community variables and monitoring of national and federal trends. Together, these recommendations will help Minnesota continue to move forward toward eliminating health disparities and creating a culture of health equity.

# Quality Measure Stratification Plan

Recommendation and Cost Estimate*	2015	2016	2017	2018
<b>Implement Statewide Education Campaign and Providing Data to Community Researchers</b>				
<b>Recommendation #1: Education Campaign</b> [\$344,000]	MDH identifies one or more vendors to assess community and provider education needs, develop and implement a curriculum, and evaluate results.	MDH and its vendors implement the campaign during 2016.	MDH and its vendors evaluate campaign.	
<b>Recommendation #2: Summary analyses</b> [\$102,000]				<ul style="list-style-type: none"> <li>• MDH assures appropriate de-identification of data for 2016 service dates and shares data or summary analysis with community researchers in accordance with the Minnesota Data Practices Act.</li> <li>• Data preparation and analysis consistent with 2017 occurs for 2017 service dates.</li> </ul>
<b>Recommendation #3: Community variable analyses</b> [\$34,000]				<ul style="list-style-type: none"> <li>• MDH makes available data set with community level (zip code) quality measure data and community variables.</li> <li>• Data preparation and analysis consistent with 2017 occurs for 2017 service dates.</li> </ul>

Recommendation and Cost Estimate*	2015	2016	2017	2018
<b>Stratify EHR-populated Clinic Measures</b>				
<b>Recommendation #4: Age, gender, zip code, and primary payer</b>  <b>[\$178,000]</b>	Data collection under way for calendar year 2014 service dates consistent with Quality Rule.	MDH conducts analysis of data obtained during 2015 and develops a project plan for stratification of subsequent data collection periods.	MDH develops summative report with stratified results starting in August 2017 that grows as quality data are reported.	
<b>Recommendation #5: Community variables</b>  <b>[\$387,000]</b>	<ul style="list-style-type: none"> <li>• MDH convenes community stakeholders and measurement experts in assessing and addressing health disparities to advise on the selection of community variables.</li> <li>• MDH obtains publicly available data sets at the zip code level and conducts preliminary analyses to inform stratification in 2017.</li> </ul>	MDH works with vendor to refine the selection of variables and a 2017 report template.	MDH develops summative report with stratified results starting in August 2017 that grows as quality data are reported.	

Recommendation and Cost Estimate*	2015	2016	2017	2018
<b>Recommendation #6/Option 1: Race, ethnicity, and language</b> [\$308,000]	<ul style="list-style-type: none"> <li>Legislature mandates that clinics submit race, ethnicity, and language by modifying MN Statutes, 62U.02.</li> <li>MDH requires reporting of race, ethnicity, and language in its update to the Quality Rule for 2016 reporting.</li> </ul>	<ul style="list-style-type: none"> <li>MDH works with vendor on education and reporting requirements.</li> <li>Clinics report race, ethnicity, and language during 2016 collection periods.</li> <li>Cost is associated with reporting additional data elements and verifying quality of data.</li> </ul>	<ul style="list-style-type: none"> <li>MDH obtains clinic quality measure data stratified by race, ethnicity, and language from its vendor throughout 2017.</li> <li>MDH develops summative reports with stratified results starting in August 2017 that grow as quality data are reported.</li> </ul>	
<b>Recommendation #6/Option 2: Race, ethnicity, and language</b> [No new costs]	<ul style="list-style-type: none"> <li>Voluntary submission of race, ethnicity, and language data by clinics to MNCM continues.</li> </ul>	<ul style="list-style-type: none"> <li>Voluntary submission of race, ethnicity, and language data by clinics to MNCM continues.</li> <li>MNCM releases updated public report.</li> </ul>	<ul style="list-style-type: none"> <li>Voluntary submission of race, ethnicity, and language data by clinics to MNCM continues.</li> <li>MNCM releases updated public report.</li> </ul>	<ul style="list-style-type: none"> <li>Voluntary submission of race, ethnicity, and language data by clinics to MNCM continues.</li> <li>MNCM releases updated public report.</li> </ul>
<b>Stratify EHR-populated Hospital Measures</b>				
<b>Recommendation #7: Race and ethnicity</b> [\$152,000]	MDH reviews developments on Meaningful Use Stage 3 and assesses recommendations from the e-Health Initiative.	In partnership with Stratis Health, MHA, and the Hospital Quality Reporting and Steering Committee, MDH works with CMS to find ways to obtain race and ethnicity summary	Assuming data has become available, MDH includes race and ethnicity reporting requirements in its update to the Quality Rule in 2017 for 2018 reporting, hospitals report race and	<ul style="list-style-type: none"> <li>MDH reports stratified results throughout 2018.</li> </ul>

<b>Recommendation and Cost Estimate*</b>	<b>2015</b>	<b>2016</b>	<b>2017</b>	<b>2018</b>
		data.	ethnicity during 2017 as per Rule.	
<b>Recommendation 8: Monitor NQF pilot</b>  [No new costs]	MDH monitors NQF pilot developments.	MDH monitors NQF pilot developments.	MDH submits a report of its findings and recommendations to the Legislature by January 15, 2017.	
<b>Stratify Patient Experience of Care Survey</b>				
<b>Recommendation 9: Patient experience of care survey</b>  [\$60,000]	MDH conducts study during 2015 and 2016.	MDH conducts study during 2015 and 2016.	MDH submits a report on its findings and recommendations to the Legislature by January 15, 2017.	
<b>Stratify Claims-based Measures</b>				
<b>Recommendation 10: Administrative transactions</b>  [\$215,000]	MDH conducts study during 2015 and 2016.	MDH conducts study during 2015 and 2016.	MDH submits a report on its findings and recommendations to the Legislature by January 15, 2017.	
<b>Stratify Measures Using Other Socio-demographic Factors</b>				
<b>Recommendation 11: Disability</b>	<ul style="list-style-type: none"> <li>Given the current lack of standard definitions of disability but ongoing discussions, MDH will</li> </ul>	<ul style="list-style-type: none"> <li>MDH convenes discussions with community members that draw on national</li> </ul>	MDH submits a report to the Legislature in 2017 with recommendations on quality measurement and	

Recommendation and Cost Estimate*	2015	2016	2017	2018
[\$141,000]	<p>monitor the efforts and report back to the Legislature by 2017.</p> <ul style="list-style-type: none"> <li>MDH studies the availability of community variables on measures of disability.</li> </ul>	<p>conversations for collecting and stratifying quality measures by disability status.</p> <ul style="list-style-type: none"> <li>MDH develops report to the Legislature for delivery in 2017.</li> </ul>	<p>disability that are aligned with the Olmstead Plan and federal standards.</p>	

\*Estimates reflect projected cost through calendar year 2018, based on assumptions discussed in “Cost Considerations” section on page 23.

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## Appendix A. Minnesota Laws, Chapter 312, Article 23, Section 10

### Quality Transparency.

(a) The commissioner of health shall develop an implementation plan for stratifying measures based on disability, race, ethnicity, language, and other socio-demographic factors that are correlated with health disparities and impact performance on quality measures. The plan must be designed so that quality measures can be stratified beginning January 1, 2017, in order to advance work aimed at identifying and eliminating health disparities. By January 15, 2015, the commissioner shall submit a report to the chairs and ranking minority members of the senate and house of representatives committees and divisions with jurisdiction on health and human services and finance with the plan, including an estimated budget, timeline, and processes to be used for implementation.

(b) The commissioner of health shall assess the risk adjustment methodology established under Minnesota Statutes, section 62U.02, subdivision 3, for the potential for harm and unintended consequences for patient populations who experience health disparities, and the providers who serve them, and identify changes that may be needed to alleviate harm and unintended consequences. By January 15, 2016, the commissioner shall submit a report to the chairs and ranking minority members of the senate and house of representatives committees and divisions with jurisdiction on health and human services and finance with the result of the assessment of the risk-adjustment methodology and any recommended changes.

(c) The commissioner shall develop the plan described in paragraph (a), in consultation with consumer, community and advocacy organizations representing diverse communities; health plan companies; providers; quality measurement organizations; and safety net providers that primarily serve communities and patient populations with health disparities. The commissioner shall use culturally appropriate methods of consultation and engagement with consumer and advocacy organizations led by and representing diverse communities by race, ethnicity, language, and socio-demographic factors.

## Appendix B: Minnesota Statewide Quality Reporting and Measurement System Measures

Table B-1: Clinic Measures

Measure	Steward
<b>Data Source: Medical Record</b>	
Optimal Diabetes Care Composite	MNCM
Optimal Vascular Care Composite	MNCM
Depression Remission at 6 Months	MNCM
Optimal Asthma Control Composite – Adult and Pediatric	MNCM
Asthma Education and Self-Management – Adult and Pediatric	
Colorectal Cancer Screening	MNCM
Primary C-section Rate	MNCM
Pediatric Preventive Care: Percent of Adolescent Patients Who Receive Mental Health and/or Depression Screening	MNCM
Pediatric Preventive Care - Overweight Counseling	MNCM
Total Knee Replacement: Functional Status and Quality of Life Outcome	MNCM
Spinal Surgery: Lumbar Discectomy/Laminotomy - Functional Status and Quality of Life Outcome	MNCM
Spinal Surgery: Lumbar Spinal Fusion - Functional Status and Quality of Life Outcome	MNCM
<b>Data Source: Patient Survey</b>	
Patient Experience of Care Survey: Clinician and Group Consumer Assessment of Healthcare Providers and Systems 12-Month Survey – Adult	AHRQ
<b>Data Source: Health Care Claims</b>	
Healthcare Effectiveness Data and Information Set (HEDIS) measures	NCQA
<b>Data Source: Clinic Survey</b>	
Health Information Technology Survey	MDH/MNCM

Notes: Medical record data is obtained from electronic health records (EHR) or paper records.  
 A Measure Steward is an organization that owns and is responsible for maintaining the measure.  
 Measure stewards are often the same as measure developers, but not always.

Source: Quality Reporting System, 2015.

Table B-2: Hospital Measures

Measure	Steward	Reporting entity
<b>Data Source: Medical Record</b>		
Acute myocardial infarction: Fibrinolytic therapy received within 30 minutes of hospital arrival (AMI-7a)	CMS	CMS
Surgical care improvement project: Cardiac surgery patients with controlled postoperative blood glucose (SCIP-Inf-4)	CMS	CMS
Influenza immunization: Influenza immunization (IMM-2)	CMS	CMS
Emergency Department Measures	CMS	CMS
Median time from ED arrival to ED departure for admitted ED patients - Overall rate (ED-1a)		
Admit decision time to ED departure time for admitted patients - Overall rate (ED-2a)		
Perinatal care (PC-01)	CMS	CMS
Outpatient acute myocardial infarction and chest pain	CMS	CMS
Fibrinolytic therapy received within 30 minutes of emergency department arrival (OP-2)		
Median time to transfer to another facility for acute coronary intervention (OP-3)		
Aspirin at arrival (OP-4)		
Median time to ECG (OP-5)		
Emergency department stroke registry indicators		Minnesota Stroke Registry Program
Door-to-imaging initiated time	Minnesota Stroke Registry Program	
Time to intravenous thrombolytic therapy	American Heart Association/ American Stroke Association	
Emergency department transfer communication composite	University of Minnesota Rural Health Research Center	MHA
Late sepsis or meningitis in very low birth weight neonates	Vermont Oxford Network	MHA
Central line-associated bloodstream infection event by inpatient hospital unit for hospitals with a neonatal intensive care unit and/or pediatric intensive care unit	Centers for Disease Control and Prevention (CDC)	Centers for Disease Control and Prevention (CDC)

Measure	Steward	Reporting entity
<b>Data Source: Patient Survey</b>		
Patient experience of care	CMS	CMS
<b>Data Source: Health Care Claims</b>		
Mortality	CMS	CMS
Hospital 30-day, all-cause, risk-standardized mortality rate (RSMR) following acute myocardial infarction hospitalization (MORT-30-AMI)		
Hospital 30-day, all-cause, RSMR following heart failure hospitalization (MORT-30-HF)		
Hospital 30-day, all-cause, RSMR following pneumonia hospitalization (MORT-30-PN)		
Obstetric trauma - vaginal delivery without instrument (PSI 19)	AHRQ	MHA
Patient safety for selected indicators composite (PSI 90)	AHRQ	MHA
Pediatric heart surgery mortality (PDI 6)	AHRQ	MHA
Pediatric heart surgery volume (PDI 7)	AHRQ	MHA
Pediatric patient safety for selected indicators composite (PDI 19)	AHRQ	MHA
<b>Data Source: Hospital Survey</b>		
Health Information Technology Survey	American Hospital Association (AHA) and MDH	AHA

Notes: Medical record data is obtained from electronic health records (EHR) or paper records.

A Measure Steward is an organization that owns and is responsible for maintaining the measure. Measure stewards are often the same as measure developers, but not always.

Source: Quality Reporting System, 2015.

## Appendix C. Stratification

Quality measures may be stratified using socio-demographic factors that are obtained at the case level, summary level, and community level. The level of granularity—or the level of detail—of the data determine what kind of stratification can be done.

**Table C-1: Types of Data and Stratification Strengths and Weaknesses**

<b>Data type</b>	<b>Description</b>	<b>Stratification strengths</b>	<b>Stratification weaknesses</b>
Case	Case-level data are granular data that are also called individual or patient data. This data can be de-identified so that the data do not identify a specific person.	Data can be combined and stratified in multiple ways; therefore, it is possible to more thoroughly identify trends and gaps in care quality, and opportunities for quality improvement.	Caution must be exercised in grouping data to guard against creating units of analysis that are so small that it is not possible to draw meaningful conclusions.
Summary	Summary-level data are case data that are grouped or aggregated into another unit of analysis. For example, de-identified patient data can be grouped into a clinic or hospital.	It is possible to identify some trends, gaps, and opportunities for improvement in clinic and hospital quality of care.	Fewer combinations of factors can be made and the amount of options for exploration are more limited.
Community	Community-level data are case data that are aggregated or grouped together by zip code, census tract, or neighborhood. For example, Census data are grouped by census tract and zip code.	It is possible to stratify quality measures using variables that are not stored in patient medical records like income and education.	Caution must be exercised in interpreting stratification results as the data lack the precision of case data.

## Appendix D. Socio-Demographic Factors

Parallel discussions are underway at the national level regarding the inclusion of socio-demographic factors for the purposes of Meaningful Use Stage 3 requirements, and stratifying and risk adjusting quality measures as evidenced by reports issued by the Institute of Medicine (IOM, 2014) and National Quality Forum (NQF, 2014b). Findings and recommendations from these reports are relevant for Minnesota to consider as it stratifies quality measures using socio-demographic factors.

IOM issued the results of its informatics study to identify social and behavioral domains and measures that providers could capture in the EHR to inform the development Meaningful Use Stage 3.<sup>34</sup> IOM recommended 11 social and behavioral domains to the Office of the National Coordinator (ONC) for Health Information Technology and the Centers for Medicare & Medicaid Services (CMS) for inclusion in future certification and meaningful use regulations.<sup>35</sup>

NQF published a report entitled, “Risk Adjustment for Socioeconomic Status or Other Socio-demographic Factors” (NQ, 2014b). The report focuses on the issue of whether to adjust performance measures for socioeconomic status and other demographic factors, including income, education, primary language, health literacy, race and other factors, and discusses the appropriate conditions for adjusting measures using socio-demographic factors. It also explored using socio-demographic factors to stratify quality measures.

IOM and NQF evaluated a number of socio-demographic factors that could be collected in the EHR and used to stratify health care quality measures. These factors include insurance status, race and ethnicity, language, country of origin, sexual orientation, neighborhood and community characteristics, employment, education, and financial resource strain.<sup>36</sup>

- *Insurance status.* According to NQF, the presence or absence of insurance may be useful for adjusting quality performance measures (NQF, 2014b). The uninsured disproportionately includes minorities, the poor, those with low education, and those with limited English proficiency. Health insurance is strongly associated with healthcare use, improved preventive and chronic care management, and reduced mortality for children and adults.

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<sup>34</sup>In 2009, Congress passed the Health Information Technology for Economic and Clinical Health Act (HITECH Act). The HITECH Act authorized new financial incentives through the meaningful use incentive program involving Medicaid and Medicare programs. The objective is to ensure that the adoption and use of health IT contributes to a more efficient, effective and safe health care system that achieves improved health outcomes.

<sup>35</sup>The IOM used the following criteria to give domains and measures high priority for inclusion in EHRs: (1) strength of the evidence of the association of the domain with health; (2) usefulness of the domain as measured for (a) the individual patient for decision making between the provider and patient for management and treatment, (b) the population to describe and monitor population health and make health care-related policy decisions that affect the population cared for by the particular health system or as a whole, and (c) research to conduct clinical and population health research to learn about the causes of health, the predictors of outcomes of care, and the impact of interventions at multiple levels; (3) availability and standard representation of a reliable and valid measure(s) of the domain; (4) feasibility, i.e., whether a burden is placed on the patient and the provider and the administrative time and cost of interfaces and storage; and (5) sensitivity, i.e., if patient discomfort regarding revealing personal information is high and there are increased legal or privacy risks.

<sup>36</sup>The IOM did not recommend disability measures for the social and behavioral domains of the next round of Meaningful Use requirements. ONC is seeking public comment on whether patient function and disability should be included in EHRs and if so, whether the International Classification of Functioning, Disability and Health should be included as a standard or whether other similar standards should be considered (ONC, 2015).

- *Race and ethnicity.* A volume of research shows variations in people's physical and mental health by race and ethnicity (IOM, 2014). People of color experience disparate outcomes across numerous health indicators compared with whites. Providers can use information on patient race and ethnicity to assess specific risks. The IOM contends that with information on their populations' racial and ethnic composition, the health system will be better able to develop, apply, and use quality metrics stratified by race and ethnicity to improve clinical services and population health, and reduce health disparities. The NQF also supports reporting quality measures stratified by race and ethnicity to assess and address disparities in healthcare (NQF, 2014b). The IOM recommended that ONC and CMS include race and ethnicity as social and behavioral domain measures in Meaningful Use Stage 3 requirements, because these measures are standard and easy to obtain in a systematic way, they are useful and feasible, and they are not sensitive.
- *Language.* Limited English proficiency contributes to suboptimal healthcare, inadequate informed decision-making, poor self-management, and healthcare disparities (NQF, 2014b). According to the IOM, collecting information about patient language is important to improving health and health care (IOM, 2009). Providers can use patient language information to target medical services and related interventions to improve care quality and reduce disparities. Lack of English proficiency is a barrier to accessing care and to effective provider-patient communications. In 2009, the IOM recommended standardized patient language data collection to foster safe, accessible, and effective quality health care.
- *Country of origin.* Individuals' health is affected by how long they have lived in the United States (IOM, 2014). First-generation immigrants tend to have better health outcomes than acculturated and U.S. born second or later generational individuals. Providers can use information about patient country of origin to improve care quality by ensuring better communication, providing appropriate care for recent immigrants and refugees, and identifying and caring for medical conditions related to exposures in the country of origin. The health system can use patient country of origin information to ensure that they have translation services and understand different cultural approaches to health care. Although knowing a patient's country of origin can be helpful to provide appropriate care, the IOM did not recommend that ONC and CMS include race and ethnicity as social and behavioral domain measures in Meaningful Use Stage 3 requirements, due to the sensitivity of such questions for patients whose immigration status is questionable.
- *Sexual orientation and gender identity.* Research shows that lesbian, gay, bisexual, and transgender people and families may face significant challenges associated with health disparities in insurance coverage and access to healthcare services, including preventive care such as cancer screenings (Office of Minority Health, 2014). The LGBTQ population experiences a number of health disparities, including a disproportionate rate of infection with HIV/AIDS (MDH, 2014). A significant structural inequity facing the LGBTQ population in Minnesota is a lack of consistent data on their health needs and concerns. The social stigma associated with being a sexual minority also threatens the quality of research as persons avoid answering questions that they feel might lead to discrimination. Disparities in mental health among the Minnesota LGBTQ population are among the most persistent and severe. CMS considered sexual orientation and gender identity measures for Meaningful Use 2, but it did not include them because of lack of consensus in public comments on whether doing so would be useful, the degree of sensitivity of the information, and how it would be recorded. The IOM did not recommend sexual orientation and gender identity measures to ONC and

CMS for Meaningful Use Stage 3 due to their limited usefulness and patient sensitivity (2014).

- *Neighborhood and community characteristics.* Research shows that neighborhood and community characteristics are useful in predicting health risk and patient care outcomes (IOM, 2014). A patient's house number and street name, city, state, and zip code plus 4-digit extension can be geocoded and linked to geographically referenced census data to characterize area socioeconomic characteristics such as air pollution data, crime rates, and walkability scores. Address information can also be geocoded to census tracts which are used to measure median household income. The IOM asserts that geocodable patient address and census tract-median household income are neighborhood indicators that can be useful when systematically included in the EHR. The IOM found that these measures are standard and easy to obtain in a systematic way from the U.S. Census Bureau's American Community Survey, they are useful at population and clinic levels, they are feasible, and providing an address to enable geocoding and the resulting census-tract information is not sensitive. The IOM recommended that ONC and CMS include geocoded residential address and census tract-median household income as social and behavioral domain measures in Meaningful Use Stage 3 requirements (2014).
- *Employment.* Employment status is strongly associated with physical and psychosocial health outcomes (IOM, 2014). Research shows that unemployed persons report lower levels of psychological well-being, have a higher prevalence of unhealthy behaviors, and experience higher morbidity and mortality than employed persons. Perceived job insecurity is also a key predictor of poor health, and job loss is linked to adverse health consequences such as increased morbidity and mortality. Additionally, aspects of certain kinds of jobs have been linked to health outcomes such as shift work and exposure to toxins. Providers can use information on their patients' employment status for diagnosis and treatment. The health system can use patient employment information to characterize their patient populations on the basis of an important social dimension which could help effectively target patients to various programs. Public health agencies could use such information to target prevention efforts and screening programs. The IOM did not recommend employment measures to ONC and CMS for Meaningful Use Stage 3 due to limited measure standardization, usefulness, and patient sensitivity (2014). NQF reported that employment status does not reflect income or availability of insurance and this factor is subject to change which then necessitates continuous updating (2014b).
- *Education.* Education level is strongly associated with income, life expectancy, and chronic disease such that higher levels of education result in greater income, longer life expectancy, and lower chronic disease rates (IOM, 2014). This relationship between education and health begins in childhood and continues throughout the life span. Children who do not receive a strong education at an early age will likely have poorer health during adulthood. One study found that the largest disparity in life expectancy is between the highest educated (post graduate degree) and the least educated (less than 12 years of education). Providers could use information on their patients' education level to better tailor communications, treatment instructions, and supports. The health system could use patient education information to influence policy changes that protect health and to encourage referrals to educational facilities. The IOM recommended that ONC and CMS include education attainment as a social and behavioral domain measure in Meaningful Use Stage 3 requirements, because it is standard and easy to obtain in a systematic way, it is useful and feasible, and it is not

- sensitive (2014). NQF noted that in the absence of an education data element in the patient medical record, community variables could be used as proxies (2014b).
- *Financial resource strain (i.e., food and housing insecurity)*. Food insecurity is associated with adverse quality of life, physical health, mental health, and nutrition (IOM, 2014). Housing insecurity is associated with poor health, nutrition deficiency, and developmental risk among young children. Homelessness is associated with poor healthcare access and high levels of unmet healthcare needs, poor health, and hospital readmission (NQF, 2014b). Providers could use information on patient financial resource strain to tailor treatment and support. The IOM recommended that ONC and CMS include financial resource strain as a social and behavioral domain measure in Meaningful Use Stage 3 requirements, because food insufficiency measurement is standardized, useful, and feasible. The IOM reported that there is not a standard measure of housing insecurity (2014).

## Appendix E: Voices for Racial Justice’s Principles for Authentic Community Engagement

Voices for Racial Justice: advances racial, cultural, social, and economic equity  
(Organizing, Advocacy and Policy) [voicesforracialjustice.org](http://voicesforracialjustice.org)

### **VRJ AUTHENTIC COMMUNITY ENGAGEMENT: A KEY TO RACIAL EQUITY**

#### **WHAT IS RACIAL EQUITY?**

Racial equity exists when all people have access to the opportunities available and outcomes are not predictable by race.

#### **WHAT IS AUTHENTIC COMMUNITY ENGAGEMENT?**

Authentic community engagement is the intentional process of co-creating solutions to inequities in partnership with people who know through their own experiences and the barriers to opportunity best. Authentic community engagement is grounded in building relationships based on mutual respect and that acknowledge each person’s added value to the developing solutions.

The Centers for Disease Control and Prevention (CDC) defines community engagement as "the process of working collaboratively with groups of people who are affiliated by geographic proximity, special interests or similar situations with respect to issues affecting their well-being."

#### **WHY COMMUNITY ENGAGEMENT?**

“Relationships we develop with our coalition partners must be transformative, not transactional.” --  
Reverend Dr. William Barber

Racial disparities are prevalent across multiple opportunity areas, from education to employment to health. These inequities hurt all of us – by weakening our economic, social, and cultural web of connection. Strengthening that web and building sustainable and transformative change requires deep partnership with communities for achieving racial, cultural, social and economic equity. This partnership is the backbone of community engagement. Rather than informing, educating, consulting, or merely having a dialogue with the community, true community engagement relies on partnerships and co-creation.

## PRINCIPLES OF AUTHENTIC COMMUNITY ENGAGEMENT

### 1. Intention leads to better process and outcomes.

*Address racism.* Authentic community engagement intentionally addresses issues of race, institutional and structural racism, discrimination and exclusion, and embodies “cultural humility.”

*Agree on the process.* The expectations, values, purpose, and role of both the institutions/systems and the stakeholder communities should be discussed and negotiated at the very beginning of any engagement process.

*Balance power.* Stakeholders should be aware of any working assumptions, and of power dynamics and how they impact the development, sustainability, and success of partnerships. They should be intentional in addressing power imbalances especially those affecting the ability of the community to act as an equal partner.

*Self-determination is a right.* “Remember and accept that collective self-determination is the responsibility and right of all people in a community. No external entity should assume it can bestow on a community the power to act in its own self-interest.” -- CDC *Principles of Authentic Community Engagement*

*Recognize different kinds of groups.* Groups often self-organize. For instance, communities organically organize beyond community-based organizations (e.g. Soccer Leagues, Churches, Barber Shops, and Coffee Shops).

*Notice assets.* Sustain efforts and support community ownership by using an asset approach, where community strengths are at the base of the work and the tool to develop capacity within communities and within your organization

*See different experiences.* Recognize, respect and appreciate the diversity/differences within and across communities. Awareness of the factors impacting communities’ ability to exercise their power (like historical trauma, oppression, disenfranchisement, etc.) must be intentionally addressed while co-creating, planning, designing, and implementing approaches to engage a community.

*Commit to communities.* Ensure that engagement efforts leave the community better.

*Stay in it for the long term.* Community collaboration requires long-term commitment by organizations involved and their partners.

### 2. Grounded in respect and appreciation.

*Work with communities.* The goal of authentic community engagement is to work WITH communities NOT FOR, on behalf of, or to do things TO communities.

*Seek authentic representation.* Make sure that representative members of the communities are authentically representing their community. They should be well-respected and have honest and genuine relationships with other members of their community.

*Understand the historical context* in which previous attempts of engagement have been occurring. What are the stories of success, lessons learned, barriers, and tensions?

*Immerse yourself in the community*, “establish relationships, build trust, work with the formal and informal leadership, and seek commitment from community organizations and leaders” to co-create (create together) solutions. -- CDC *Principles of Authentic Community Engagement*

*Recognize the contributions* of the community.

*Allocate resources* for community members to be active participants, so that community engagement is valued for its contribution to the process (e.g. offer stipends, child care, food, interpreters).

### **3. Tension and partnership work together.**

*Address challenges.* Develop a plan to address conflict, being intentional and strategic to transform challenges into opportunities.

*Share power.* Be ready to share power (release control of actions and/or interventions) with communities, and be flexible and creative to meet its changing challenges

*Expect tension.* Authentic engagement is not necessarily easy or peaceful. Partnership in a change process will sometimes result in tension. Partners will challenge and hold each other accountable for staying true to principles for engagement and to goals for racial equity.

## Appendix F: Community Survey Information and Responses

Voices for Racial Justice interviewed 85 members of diverse communities disproportionately impacted by health inequities. Summary demographic information is displayed in Table F-1. Interviewees self-identified demographic information, including multiple racial identities and other socio-demographic factors. In conducting these interviews, Voices for Racial Justice did not share interviewee names with MDH.

Table F-1: Community Interviewee Self-reported Information

FACTOR	%
<b>Age:</b>	
18 to 35 years	40
36 to 88 years	60
<b>Geographical Location:</b>	
Living within the Twin Cities Metropolitan area	71
Living outside the Twin Cities Metropolitan area	29
<b>Race:</b>	
American Indian/Native American	26
Black-African American	32
African Immigrant	13
Native Hawaiian or other	7
Pacific Islander	2
White <sup>a</sup>	13
Some other race	6
Decline	1
<b>Ethnicity:</b>	
Hispanic or Latino	21
Not Hispanic or Latino	78
Declined	1
<b>Language Preference for Health Care Information:</b>	
Reading – English	64
Listening – English	66
<b>Country of Origin:</b>	
United States	55
Other	45

FACTOR	%
<b>Health Insurance:</b>	
No health insurance	9
Government insurance <sup>b</sup>	32
Employer based insurance	47
<b>Income Level:</b>	
Below 250% Federal poverty level	53
<b>Disability:</b>	
People with disabilities	16
<b>Sexual Orientation:</b>	
Other than heterosexual	31

<sup>a</sup>Out of the 11 interviewees who chose White as their race, 9 self-identified as Hispanic/Latino, and 1 as Arab born in Egypt.

<sup>b</sup>Government insurance includes Medicare, Medicaid, and MinnesotaCare.

Source: Voices for Racial Justice, 2014.

**Table F-2: Interviewed community members who responded, “Yes, I would answer a provider’s question about [factor]”.**

Factor	American Indian/ Native American (22) %	Black/ African American (11) %	African Immigrant (6) %	Asian Pacific Islander (27) %	Latino/ Hispanic (18) %	LGBTQ- Two Spirit (12) %	People with Disabilities (14) %
Age	96	100	83	96	89	100	79
Zip code	96	91	100	93	83	100	79
Race	96	100	100	96	72	100	93
Ethnicity	86	82	100	100	78	83	64
Language	96	100	100	100	78	100	100
Country of origin	91	91	83	93	67	92	79
Disability	86	100	100	89	83	92	93
Sexual orientation	73	73	33	82	56	67	36
Gender identity	100	82	100	96	72	92	86
Income	59	73	50	48	56	67	79

Source: Voices for Racial Justice, 2014.

Table F-3: Interviewed community members' preferences for how, with whom, and when to share socio-demographic information with providers.

	American Indian/ Native American (22) %	Black/ African American (11) %	African Immigrant (6) %	Asian Pacific Islander (27) %	Latinos/ Hispanics (18) %	LGBTQ- Two Spirit (12) %	People with Disabilities (14) %
<b>How</b>							
Paper-based form	36	27	17	22	28	17	29
Electronically	9	9	17	22	6	8	7
Verbally	46	36	17	11	67	67	36
No preference	0	18	33	22	0	0	14
Combination	9	9	17	22	0	8	14
<b>Who</b>							
Front desk	23	27	0	22	28	17	29
Medical assistant/nurse	41	9	34	11	22	33	21
Provider	9	18	17	33	44	17	21
Combination or no preference	27	46	50	33	6	34	28
<b>When</b>							
Check-in	50	36	33	41	28	33	57
Phone	0	0	0	11	0	0	0
Exam room	41	36	33	19	72	67	36
Other	9	27	34	29	0	0	7

Source: Voices for Racial Justice, 2014.

## Appendix G: Community Recommendations

Voices for Racial Justice (2014) synthesized past recommendations and plans from the following reports:

- Collection of Racial/Ethnic Health Data by the Minnesota Departments of Health and Human Services. (January 2011)<sup>37</sup>;
- Race, Ethnicity and Language Work Group Recommendations to the Governor’s Health Care Reform Task Force. (May 2012)<sup>38</sup>; and
- Advancing Health Equity in Minnesota.” Minnesota Department of Health (February 2014).

Voices for Racial Justice states:

- The 2014 legislation recognizes that the time has come for the state to act on the plans and recommendations that have been made in a number of significant state agency, task force and commission reports dating back to 2011 that addressed the inadequacies of current data collection and reporting methods in identifying and addressing health disparities experienced by RESD populations. The 2014 legislation calls for an implementation plan and budget for moving forward with changes to statewide data collection and reporting methods.

Voices for Racial Justice calls this summary, “The Framework of a State Health Equity Plan to Make Health Disparities Visible.”

- 1) **Identify and measure health disparities for each RESD population.** Minnesota’s serious health disparities experienced by racial, ethnic and socio-demographic (RESD) populations cannot be effectively addressed unless the disparities experienced by each RESD group can be identified and quantified through health care data.
- 2) **Expand and improve RESD categories.** Existing categories for dividing data by race, ethnicity, language and socio-demographic factors are inadequate. More detailed categories are needed and the categories must be developed in partnership with the RESD communities so that they match the ways in which RESD community members identify themselves. Data collection systems should be designed with flexibility so that categories can be changed in the future as needed to adapt to state demographic changes. Categories should be more expansive and granular than national U.S. Office of Management and Budget (“OMB”)<sup>39</sup> standards, but should be able to be aggregated into the OMB standards.
- 3) **Establish a statewide standard construct for RESD data.** A uniform data construct should be developed so that all health data collected uses the same categories for race, ethnicity, language and socio-demographic factors. The uniform construct should be used by the Minnesota Department of Health and the Minnesota Department of Human Services, but also by licensing boards, governmental agencies, health plans, hospitals, clinics, health care homes, nonprofit agencies, quality and performance measurement programs and others who collect, analyze and report health data. All entities that are required to collect maintain or report health data or who

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<sup>37</sup>Recommended Questions and Variables for Standard Race, Ethnicity, and Language Data Collection. Retrieved from [mn.gov/commerce/insurance/images/ExchATF-RELquestions-variables8-29-12.pdf](http://mn.gov/commerce/insurance/images/ExchATF-RELquestions-variables8-29-12.pdf).

<sup>38</sup>Recommended Questions and Variables for Standard Race, Ethnicity, and Language Data Collection. Retrieved from [mn.gov/commerce/insurance/images/ExchATF-RELquestions-variables8-29-12.pdf](http://mn.gov/commerce/insurance/images/ExchATF-RELquestions-variables8-29-12.pdf).

<sup>39</sup>[www.whitehouse.gov/omb/fedreg\\_1997standards/](http://www.whitehouse.gov/omb/fedreg_1997standards/)

participate in health data measurement and reporting programs should be using the expanded RESD categories and following the statewide standard construct.

- 4) **Improve methods of obtaining RESD information.** Methods of requesting information from patients on their race, ethnicity, language and socio-demographic factors should be improved. Different methods of asking for and collecting RESD information are needed for the different populations to reflect the different ways in which each population interacts with the health care system, health care providers and governmental agencies. Methods of requesting RESD information should include informing patients about why the information is being requested, how it will be used, and how the privacy and security of the information will be protected. Training and tools should be developed for use by those organizations and staff persons who are responsible for obtaining health care information from patients. Methods, training and tools should be developed in authentic partnerships with the RESD communities themselves.
- 5) **Protect and preserve health data privacy and security.** All changes to health data collection and reporting systems and methods must be made in ways that protect and preserve the privacy and confidentiality of information about individual patients and in full compliance with laws governing data privacy and security. Public reports on health disparities of RESD populations should only contain aggregated, summary data that does not identify individual patient information.
- 6) **Authentically partner with RESD communities.** State and local governmental agencies, health care organizations and policymakers should develop and implement health equity data policies and systems in partnership with RESD communities using authentic community engagement methods that enable RESD communities to participate in policymaking and system change that directly affect them. Aggregate, summary data on health disparities should be made freely available to RESD communities so that they can identify and address the disparities their members' experience.
- 7) **Establish a long-term state health equity data plan.** A long-term plan is needed for improving health data systems to better identify, quantify and address health disparities, including the actions and activities that are needed and a timeline and budget for implementation. The elements of the plan are described in more detail in the Minnesota Department of Health's report on "Advancing Health Equity in Minnesota."

The following recommendations are based on the community engagement activity undertaken by Voices for Racial Justice on behalf of MDH in response to the 2014 legislation. These recommendations are intended to supplement and expand the previously delineated recommendations.

- 1) **Improve Categories of Race, Ethnicity and Language (REL).** The "Recommended Questions and Variables for Standard Race, Ethnicity, and Language Data Collection"<sup>38</sup> are an acceptable set of categories to use as a starting point to collect REL data. However, the categories should continue to be evaluated, modified and continuously improved. In particular, more work is needed to improve questions and categories for Black/ African American and American Indian/Native American Communities.
- 2) **Develop Other Socio-demographic Data Categories.** Income, gender identity, sexual orientation and disabilities are sensitive and personal questions. Additional work is needed to develop categories for these characteristics and methods of asking patients and consumers for this information, including ways to explain why this data is important and how it will be used and shared.
- 3) **Explain Data Privacy and Security Protections.** When RESD information is requested, consumers and patients should be informed about how current health data privacy and security

laws protect their health care information from misuse or disclosure. Explaining these protections is likely to improve their willingness to provide the information requested.

- 4) **Communicate the Purpose and Use of RESD Data.** Consumers, patients and RESD communities would benefit from understanding why RESD information is needed and how it will be beneficial to patients and communities. The benefit and potential impact of collecting socio-demographic data needs to be clearly defined and communicated with patients, consumers and communities. Consumers, patients and communities should be reassured that their treatment will not be negatively impacted by their RESD factor(s), income or ability to pay for the services needed. Public awareness and education about this should be undertaken both within the health care system at the individual patient or consumer level and in the larger community.
- 5) **Build Community Trust of the Health Care System.** There is a general issue of lack of trust which needs to be acknowledged by those who work in and lead health care organizations. Many interviewees expressed fear that their socio-demographic data would be used against them. To improve trust, there is a critical need for health care organizations to hire people who look more like the people they are working with and share their RESD factors.
- 6) **Provide Training on community engagement methods.** Health care organizations would be better able to improve care and reduce inequities by learning best practices for authentically engaging RESD communities disproportionately impacted by inequities. Training is critical in order to build the trust that is needed to better serve RESD patients and reduce inequities. Training should include learning how to understand and address institutional racism and discrimination.
- 7) **Make Aggregate Health Equity Data Available to Communities.** A plan to make data collected available to the community should be developed by every health care organization and by research, public health and quality measurement organizations that collect health data. In addition, MDH should become more intentional in making RESD data accessible not only to mainstream organizations but to RESD communities and the broader community in general. Socio-demographic data collected by the health care system should be used to create public reports easily accessible online. This transparency of the process will motivate actions and collaborations between systems and communities, which in the end will make everybody accountable to create a healthier community. The dissemination of this information is part of MDH's role in collecting information "used to inform policy makers, consumers, and other stakeholders in Minnesota's health care system."<sup>40</sup> Community access to this information on inequities is an essential element to succeed in efforts to create a healthy community by expanding the possibilities for government and health care system leaders to co-create solutions with the affected communities. It will make it easier to identify needs and set priorities for the allocation of resources that are more equitable. It will also enhance the opportunity to improve quality of health care services and patient experience while decreasing costs. Information should be widely disseminated in multiple forms, not only digitally but also in various written forms. The language used should be understandable not only by the experts, but by community-based organizations and regular citizens.
- 8) **Develop Inclusive, Culturally Appropriate Methods of Collecting RESD Data.** The collection of RESD data should be undertaken in ways that are culturally appropriate for the particular patient or RESD community. The best way to achieve this goal is by intentionally involving the communities in developing and implementing the plan for how to collect, use and share this data.

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<sup>40</sup>[www.health.state.mn.us/health/economics](http://www.health.state.mn.us/health/economics)

Further, different methods are appropriate for different patients and communities. Because most respondents expressed a preference for data to be collected using either paper forms or being asked verbally, rather than requesting the information electronically, it may be preferable to use a combination of both written and verbal requests, such as general questions about Race Ethnicity and Language (REL) and Socio-Economic Status (SES) can be collected by paper at registration at the clinic, and more sensitive information such as gender identity, sexual orientation and disability requested in the exam room by the health care provider, nurse or medical assistant. Language used for the questions should be at 6<sup>th</sup> grade level or lower in order to be understandable to as many patients and consumers as possible. The plan for collecting the information should be designed to avoid people being asked multiple times for the same information.

- 9) **Develop a uniform construct for collecting RESD data across all systems.** Socio-demographic data needs to be collected using consistent standards across the entire health care system in the state to be able to make comparisons around quality improvement. This is an important recommendation of earlier reports. This will make the efforts more effective by allowing data from multiple sources to be used and to allow comparisons of outcomes in different parts of the system. Further, other governmental agencies and systems beyond health care—such as education, housing, transportation, social services, etc.—should also use the same uniform standards for collecting RESD data. This will create better opportunities to collaborate across different parts of government and society and allow development of a more comprehensive strategy for achieving healthier communities.
- 10) **Understand Providers’ Perspectives on Collecting RESD Data.** Safety Net Providers serving high concentrations of RESD patients and communities should also be consulted in developing the plan for implementing RESD data changes. Those interviewed for this report recommended the following changes to improve data on disparities:
  - Additional RESD data categories that should be explored are:
    - Mental health
    - Housing stability
    - Employment status
    - Education level
    - Social support
    - Health literacy
  - Statewide provider quality measures should be risk-adjusted to reflect RESD status of patients and populations served. Adjustments must go beyond race, ethnicity and language to also include additional social determinants of health and socio-demographic risk factors that have an impact on health, access to services, quality of care, patient satisfaction and other health system quality indicators.
  - Comparison of rural and urban populations.
  - The state has a vital role in advancing RESD data stratification and risk adjustment methods. The science and existing practices are still emerging. The state should commit resources and expertise to improving data collection and risk adjustment methods in order to better identify and address health disparities.
- 11) **Understand Social Determinants of Health.** Interviewees felt that there is also a need for greater awareness and understanding by people who work in the health care system of how social determinants like economic status and challenges around jobs affect the health and patients and communities.

- 12) **Develop Awareness of Structural Racism and Discrimination.** Health care providers, health care professionals, and health care and government leaders within Minnesota's health care system would benefit from understanding how structural racism and structural discrimination based on socio-demographic factors has adversely impacted RESD communities and patients as well as the entire community at large by increasing health disparities. With increased awareness they will be better prepared to be intentional in changing the system.
- 13) **Recognize Challenges New Immigrants Face.** The systems need to recognize that immigrants face unique challenges which are impacting their health and treatment. This situation is even more challenging for immigrants who are undocumented and even less likely to provide RESD data or to trust that the information provided will not be used in a way that will negatively impact them.
- 14) **Work with Communities to Improve Health Equity Data.** The health care system needs to work with communities to define and then communicate how socio-demographic data collected will be used and shared. Assessing the challenges and strengths of communities disproportionately impacted by health inequities should be an ongoing effort.

## Appendix H: Acronym Reference

Acronym	Definition
ACA	Federal Accountable Care Act
APCD	All Payer Claims Database
AHRQ	Agency for Healthcare Research and Quality
BPHC	Bureau of Primary Health Care
CG-CAHPS	Clinician and Group Consumer Assessment of Healthcare Providers and Systems
CMS	Centers for Medicare & Medicaid Services
DHS	Minnesota Department of Human Services
EDI	Electronic Data Interchange
EHR	Electronic Health Record
EMR	Electronic Medical Record
FQHC	Federally Qualified Health Centers
HCAHPS	Hospital Consumer Assessment of Healthcare Providers and Systems
HEDIS	Healthcare Effectiveness Data and Information Set
HIPAA	Health Insurance Portability and Accountability Act
HIT	Health Information Technology
HITECH Act	Health Information Technology for Economic and Clinical Health Act
HRSA	U.S. Department of Health and Human Services Health Resources and Services Administration
IOM	Institute of Medicine
LGBTQ	Lesbian, Gay, Bisexual, Transgender, Queer/Questioning
MDH	Minnesota Department of Health
MHA	Minnesota Hospital Association
MMA	Minnesota Medical Association
MN	Minnesota
MNCM	MN Community Measurement
MU	Meaningful Use
NCQA	National Committee for Quality Assurance
NQF	National Quality Forum
OHIT	Office of Health Information Technology
OMB	Office of Management and Budget

Acronym	Definition
ONC	Office of the National Coordinator for Health Information Technology
REL	Race, Ethnicity and Language
RESD	Race, Ethnicity and other Socio-demographic factors
SDH	Social Determinants of Health
SQRMS	Minnesota Statewide Quality Reporting and Measurement System
UDS	Uniform Data System
VRJ	Voices for Racial Justice

